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ABSTRACT

Presented are nine papers given at a 1972 Washington State conference on the rights of the mentally handicapped for state attorneys and professionals in the mental retardation and mental health fields. The keynote address, by the Honorable David Bazelon focuses on the Wyatt vs. Stickney Alabama court case which affirmed the right to treatment of institutionalized patients. The administrator's perspective on the rights of the mentally handicapped is considered in three papers. The implications of recent litigation involving the rights of the mentally retarded is reviewed by Robert Gettings. David Ray looks at past, present, and future trends in state program development. Discussed by Philip Roos is the role of private organizations such as the National Association for Retarded Children. The attorney's perspective on rights of the mentally handicapped is centered on in three presentations: Bruce Ennis answers questions on the National Council on the Rights of the Mentally Impaired; Thomas Gilhool summarizes the Pennsylvania Right to Education suit; and Sterling Ross reports on the status of the mentally retarded under California law. Also given is a panel discussion on the Wyatt vs. Stickney right to treatment case. The results of workshop/discussion groups on current and future trends in the protection of legal rights of the mentally handicapped are reported. An annotated bibliography of 27 items on the right to treatment and the right to an education is also provided as is a glossary of legal terms, a position paper on peonage, the conference agenda, and sources of information. (DB)

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THE RIGHTS OF THE MENTALLY HANDICAPPED:

PROCEEDINGS FROM A BI-REGIONAL CONFERENCE

SAN FRANCISCO, CALIFORNIA
JUNE 14–16, 1972

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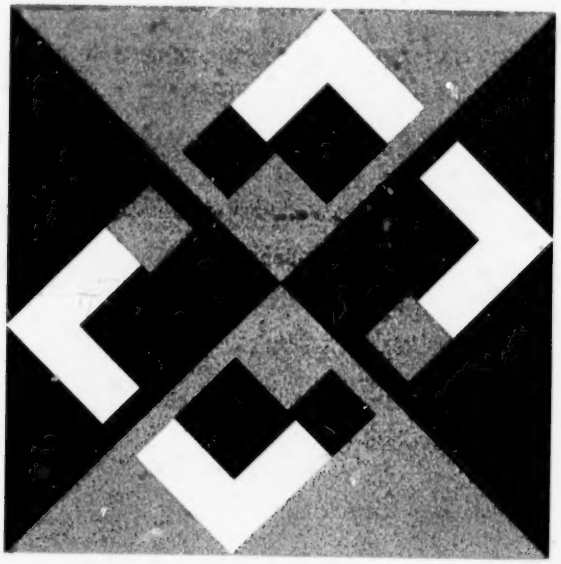

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The development of any major conference always involves the cooperative labors of many people. The conference upon which these proceedings are based is no exception.

Much of the credit for conceiving the idea of the conference, pursuing the necessary funding and designing the program format belongs to Dr. Samuel L. Ornstein, Chief of the Washington State Office of Developmental Disabilities and the conference chairman. However, the conference never would have taken place without the organizational and managerial skills and dedication of the staff of the Washington Office of Developmental Disabilities. Special recognition should be given to Mr. Philip Benson, who so ably coordinated the development of the program and the arrangements for the conference, and Mrs. Patricia Moore, who handled the myriad details involved in conducting the meeting. Mr. Benson and Mrs. Moore also managed the laborious tasks of recording and transcribing the conference proceedings and obtained edited transcripts from the various speakers and panel participants.

Final editing, printing and distribution of this publication was accomplished by the staff of the National Association of Coordinators of State Programs for the Mentally Retarded, Inc., under the general direction of the Association's Executive Director Mr. Robert M. Gettings. Mr. Wm. Allen Ziegler, Jr. was responsible for coordinating the design, layout and printing of the final publication and assisting with final editing. Ms. Jane Hawks detail-edited the final manuscript and prepared the final camera-ready copy as well as coordinating distribution of the publication.

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Preface

In the Spring of 1972 the State of Washington found itself attempting to grapple with a number of chronic problems involving the human rights of institutionalized retarded persons. None of these problems were new. Many had, over the years, been either partially or completely dealt with. Nevertheless, our awareness of the depth and chronic nature of the situation was sharpened by the realization that throughout the country, other groups of people were attempting to provide solutions by means of legal intervention.

Having some thought that there would be a tendency for state agencies, local authorities and citizens to passively await some kind of Olympic judgment by the courts, it was decided that a conference should be called to ensure that the people responsible and interested in this area take a proactive rather than a reactive stance toward these problems. Through interchange with other knowledgeable state officials and lawyers and with the help of certain involved national consultants, a forum for constructive interaction was developed.

Participants were selected and an agenda was drawn up with the following objectives in mind:

1. To bring together representatives from the states' attorney general offices and the mental retardation and mental health agencies for the education of these groups.

2. To draw on the experience of those states which have reached solutions to questions concerning human rights and to share their knowledge with other states where these problems still exist.

3. To appraise the problems and their solutions from the viewpoint of the state officials, the state attorneys and their adversaries who were seeking legal redress for mentally handicapped clients, and to establish productive solutions to situations which may arise on the West Coast.

4. To consider possible revision of statutes in an attempt to make the laws conform with present day views concerning the human rights of the people entrusted to the state for twenty-four hour care.

We assumed during the development of this meeting that close relationships existed between state attorneys general and those state officials responsible for mental retardation and mental health programs. Interestingly enough, this did not appear to be true. It was obvious that the relationship between those persons responsible

for programs in the state and their legal "representative" was a tenuous one. It seemed that the opinions of the attorneys general were often addressed to areas of rather small and relatively petty questions of administration; rarely were they asked for advice on the legal ramifications and philosophy concerning the incarceration of people who had been adjudged mentally retarded or mentally ill.

It was interesting, in view of the intense publicity given to such cases as the Partlow, Willowbrook, and Pennsylvania litigation, that a number of professionals, both in the area of mental health and mental retardation, and lawyers who had responsibility for these areas, were unaware of the situation in any significant way.

The conference succeeded in making the participants aware of the implications of present court cases and the obviously more important question of the human rights of the mentally retarded and mentally ill. It also succeeded in making each group aware of the needs, perspective and problems of the other. Whether it succeeded in its most important goal - i.e., to prepare the state, through its attorneys and its other civil servants for a more aggressive response to the human rights needs of its citizens - remains to be seen.

Rather than printing the conference materials in their actual chronological sequence, the proceedings have been broken into several sections, with the major alterations being the grouping of what might be called observations from the attorney's perspective separated from the program delivery perspective. While this separation is directly in opposition to the basic theme of the conference, that being the coordination of legal and program-oriented services, it is hoped that through this manner both the similarities and differences of viewpoint of the two groups may become more readily apparent to the reader. A copy of the original agenda has also been included in Appendix D for your information.

For those readers who want to keep abreast of developments in the litigation arena, several agencies and organizations provide information and digests on current court cases. These include the National Center for Law and the Handicapped, South Bend, Indiana; Council for Exceptional Children, Arlington, Virginia; Office of Mental Retardation Coordination, HEW; the Center for Law and Social Policy, Washington, D.C.; and the National Council on the Rights of the Mentally Impaired, Washington, D.C. The complete addresses for these groups may be found in Appendix E.

In Appendices A and B, you will find an annotated bibliography and a glossary of terms which we hope will assist the lay reader and student of the subject area. The materials in these appendices have been reproduced from the April, 1973 issue of Mental Retardation and the Law, a periodic booklet published by the

Office of Mental Retardation Coordination, Department of Health, Education, and Welfare. You may obtain copies of the latest issue in this series of reports on the current status of pending and completed litigation by writing the Office of Mental Retardation Coordination.

In a publication of this type it is impossible to convey the full sense of personal interaction which took place at the conference. Nonetheless, we trust that readers will gain a feeling for the important issues involved and the need for better understanding and interaction between the legal profession and professional workers in the fields of mental retardation and mental health.

The following, then, are the proceedings from this conference, published in the hope that others concerned and involved with the rights of the mentally handicapped may share some of the benefits derived by the original participants.

Samuel L. Ornstein, Ph.D.
Conference Director

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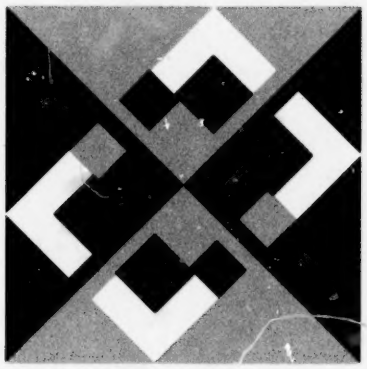

KEYNOTE ADDRESS

The Judicial Process - A Tool for Reform

The Honorable David L. Bazelon

When I first read Judge Frank Johnson's opinion in Wyatt v. Stickney, I couldn't help thinking of a story told to me several years ago by an eminent and most thoughtful lawyer. The occasion he described was in the Supreme Court of the United States. Nine Justices were assembled at the then customary Monday sessions at which the opinions of the Court were delivered orally. One case involved the deportation of an immigrant who had lived and worked and raised his family in this country for 40 or 50 years. Mr. Justice Frankfurter, in the majority, delivered an opinion affirming this man's deportation. Felix Frankfurter built his case in what can only be described as his "airtight fashion" -- with each legal joint perfectly fitted to its appropriate socket. The lawyer who told me this story, and whose sympathies lie entirely with the immigrant, told me that by the time Frankfurter was through, he too was convinced that the result was not only inevitable but so obvious he couldn't see how he could have missed it!

Mr. Justice Black, who had been reclining most peacefully during Frankfurter's discourse, then slowly leaned forward at the bench; slowly crossed his arms and bent over the bench and addressed the entire bar: "Gentlemen, I just don't think we mean to do people that way."

You asked me here because you are concerned about the impact of judicial decision on the treatment programs for the mentally handicapped -- programs for which you men and women bear the crucial responsibility. You asked me here to tell you how to respond to cases like Wyatt, and like Rouse v. Cameron, the case in which the "right to treatment" sprouted some of its earliest judicial roots five years ago. But it is said that a consultant is only a person who borrows your watch to tell you what time it is. You are asking me to tell you about something that you live with everyday -- that we don't mean to "do" people this way.

The judicial pronouncements of a right to treatment must first of all be understood on two levels. At the first level, if the state is going to maintain institutions that it calls "hospitals" or treatment facilities, it has to maintain humane and decent physical living conditions and make bona fide efforts to care for its charges. This was the basic message of the Rouse decision and the dramatic message of Wyatt. At a second and much deeper level, however, the right to treatment decisions raise questions of such enormous moral and legal complexity that courts have not even begun to address them. I want to talk about both of these levels.

Since this conference was organized in the wake of the Wyatt decision, I take it that one of your purposes is to decide how you

should respond to it. You could take the position of paying lip service to the obvious human decency it expresses, while at the same time remaining suspicious. angry and defensive about the criticism of, and the judicial interference in, your professional domain. I would not be surprised at this reaction since after Rouse was decided, the APA's immediate response was to tell the courts "Hands off -- this is our business."

On the other hand, you could take the position of responding to Wyatt with relief and joy. After all, if the law -- the all-knowing father figure -- had spoken, won't all the problems disappear? Under that response, Wyatt v. Stickney harkens the millenium.

Before arriving in San Francisco, I really had no way of knowing what your reactions to the decision would be. I couldn't take a poll. (Perhaps I could have added another referendum on your ballot last week, and kept the polling places in San Francisco open at least until midnight.)

In any case, I want to speak to both of the responses I mentioned. If you are worried and frightened, I want to allay some of your fears about the right to treatment decisions. If you are relieved that the end of your struggles is in sight, I want to warn you that they are just beginning.

First to those who have fears that judges will be breathing down your necks:

The primary thrust of Wyatt, and of litigation prior to it, has been against conditions of neglect and mistreatment so outrageous they cried out for reform. For example, in a 1968 decision, the New York Court of Claims awarded a Mr. Whitree three hundred thousand dollars in a tort action for his pain, suffering and lost earnings during twelve years and four months he had spent "incarcerated" -- as the Court termed it -- in Matteawan State Hopsital.

The Court found the basis for its judgment in Whitree's hospital record, which the Court called "about as inadequate a record as we have ever examined." A medical expert also testified to its inadequacy, but the Court held that "it was so inadequate that even a layman could determine that fact."

In holding the State liable for negligent medical care, the Court acknowledged that errors of professional judgment may not entail liability provided the professional does what he thinks best after a careful examination. The Court however found, and here I am quoting from the opinion:

> *Careful examination was totally lacking over this 14 1/2 year period. We find that no competent professional judgment was made. We find only custodial judgment. In fact, the trial record developed clearly*

and coldly that the claimant received only custodial care during the greater part of said confinement: and that, in part, said custodial care was brutal and callous. The record is, in fact, redolent with callous contempt for the claimant herein.

The conditions of the Alabama institutions revealed in Judge Johnson's courtroom were equally brutal and callous. When state officials looked straight at the inadequacies of their own hospitals they knew that they couldn't be defended. They agreed with that other Alabaman, Mr. Justice Black, that "we just don't mean to do people that way." With the consent of these Alabama officials, standards of minimum humane treatment were finally written into a court order. I do not believe that the administrators and physicians acquiesced out of fear of court action, but rather out of their own shame and guilt.

It's perhaps very easy to assume that what judges are eager to do is embroil our courts in complicated disputes over professional medical judgment and about competing forms of therapy. But in reality, courts want to be able to deal with you as we deal with all persons who apply their own expertise in exercising the power of the state. We want to rely on you to make your own decisions.

We judges are no more authorized or equipped to tell a hospital to apply a particular therapy for a "chronic undifferentiated schizophrenic" than we are to tell the Federal Communications Commission to allocate a specific AM frequency. In both situations, we are only concerned whether the administrative officials have observed the constitutional and legislative mandates for ensuring that the path to decision is tread deliberately and carefully, that appropriate alternatives have been considered, and that substantive results are not patently illegal. So unless they are faced with conditions of treatment "so inadequate even a layman could determine that fact," judges are not going to make your decisions for you.

Of course, to make the kind of drastic improvements in treatment facilities and procedures which Wyatt has ordered, more funds will have to be obtained. No one could dispute this. I cannot urge you strongly enough to continue your struggle for more resources, and decisions like Wyatt are helpful in that they dramatically expose the need. But money is not the key to victory, even on the level of abuse to which Wyatt speaks. What does it really mean to be able to hire three hundred more people? Those numbers raise even more questions about the qualifications of those people, their training, their ability to treat the patients they will care for on a human level. To put it as bluntly as possible, we have to ensure that these three hundred new employees will not do more harm than good.

So to those of you who are rejoicing over decisions like Wyatt, I think you have real reason to welcome them. But don't be unrealistic in your expectations of what they can accomplish. Court orders alone will not usher in the millenium.

I have several reasons for warning you against false hopes and expectations of judicial action and activism.

First of all, judicial activism is no longer such a sought-after commodity. Only last week, for example, the U.S. Court of Appeals for the Fourth Circuit struck down a Virginia District Judge's decision that is in some ways less "radical" than Wyatt. The Virginia judge had ruled that white suburban schools would have to integrate with the overwhelmingly black schools of the city of Richmond as the only means of achieving real integration. This was the first court to order integration between independent city and county school systems.

The Appeals Court branded this decision "beyond the power of a district court." It seemed to count for nothing that what the court had ordered was the only way to end the segregation in Richmond which was depriving thousands of children of their rights to an equal education. Increasingly judges are being told that they are powerless to effect change, although it has been established for eighteen years, since Brown v. Board of Education, that courts must examine the inequalities in our schools.

That is why you must not be complacent in thinking that courts either can or will find ways to solve all your problems -- to provide treatment for all the patients who are being denied their rights. Judges like Frank Johnson are courageous enough to order the minimum that justice and decency demands -- but the full remedy for the right to treatment will never come from the courts.

In the second place, decisions like Wyatt are limited even in terms of what they seek to accomplish. The institutions in Alabama are, after all, only a small fraction of our entire problem. And even in that one state Judge Johnson could not possibly provide rules and regulations to cover very crucial contingencies in the implementation of the minimum standards of adequate care. I can promise you that such a handbook will never be written for you in court.

You are, after all, a very important part of the power structure which must implement these standards. No court is ever going to order them without your testimony; no legislature is ever going to vote more funds without your explanations and request. It is your task to clean up conditions, if they exist in your state, which you would be ashamed to defend.

Thus, an undeniably important part of your response to Wyatt should be to discuss here at this conference what you can do now to avoid even the threat of a similar court action in your state. But don't forget that establishing the fundamental preconditions to a treatment program is not going to take all the steam out of the right to treatment decisions. As I stated earlier, to even begin to make sense out of these decisions we have to take a look at some major questions which only a few have encouraged us to ask. Whether or not we agree with his answers, Dr. Thomas Szasz has at least been asking questions that must be confronted.

For example, what qualifies as "treatment" for the mentally handicapped? Who should be singled out for treatment? When can treatment be imposed, and for how long? There are no court decisions on these most important questions, and they certainly could not be resolved in any single judicial opinion. I therefore propose that we at least begin to examine them, because the very existence of the treatment programs instituted in your states indicates that we are in fact taking positions on these issues without being able to say that we have first thought them through.

There is a great temptation to assume that if we could only encourage more voluntary admissions that all these hard issues would go away. While I have welcomed the increasing movement toward voluntary acceptance of treatment, I am disturbed by the many legal distinctions drawn between the "voluntary" and "involuntary" patient, which assume that differences flow from these labels without any regard for the underlying realities.

I can illustrate this point, I think, by describing to you a very disturbing incident which occurred when I was in the Soviet Union as a member of the First U.S. Mission on Mental Health to the U.S.S.R. At the close of our five to six week stay in Russia, our group met with the Minister of Health to discuss our final questions and impressions. Concerned with the questions that arise at home in the District of Columbia, I asked what percentage of the patients occupying mental hospitals in the Soviet Union had been committed involuntarily. The Minister replied two to three percent! I was amazed at this low figure, and asked how the Russians defined "involuntary" hospitalization. We were told that a patient is considered voluntary so long as he wants to go into the hospital; or his family wants him to go; or his party or factory unit wants him to go.

We all laughed a little, quite respectfully. But as we departed in our car, one of the members of the Mission, a psychiatrist in charge of one of the largest state mental hospital systems in this country, turned to the rest of us and said: "Why are you fellows laughing? Is it really much different at home?"

My laughter stopped. After all, we too often simply tell people that if they don't go willingly, they'll just go anyway. And it's hard for me to think of mentally disabled children committed by their parents as "voluntary" patients. Inherent in the concept of voluntary action is a free choice among alternatives -- at least the opportunity to consider alternate courses of action. If there is only one place to go -- if real treatment and placement alternatives do not exist for the mentally handicapped -- then we are only pretending that there can be "voluntary" patients.

At the outset, we must consider whether "treatment" must always mean the provision of skills and techniques which the mental health professions offer. There are, after all, patients who refuse to accept any form of treatment. And there are patients who don't

improve, who can't be treated in your facility, or who don't need treatment but have nowhere else to go. Should these people be kept locked up, or locked away? Isn't sending them home also a form of treatment? What other questions do their cases raise about the limits of your expertise?

There are other conflicts posed for you: What do you do when a patient disputes your treatment plan? Or wants to be released from treatment earlier than you feel is best? Do you have the absolute right to treat him? How do you decide whether to release patients into the community who no longer need your treatment but who may still be dangerous?

I don't see why you should wait to confront these problems until cries of outrage are upon you. For example, you may have heard the allegations that political dissidents in the Soviet Union are being locked up in prison hospitals. I'm sure you would roundly condemn the Russian psychiatrists who diagnose and label people as "sick" for defying the political order. Such decisions abuse the tools of psychiatry by abandoning the interests of the individual in order to serve only the interests of the state.

As documents supporting these allegations found their way into this country, the American Psychiatric Association decided to look into the charges, and appointed an Ad Hoc Committee on the Use of Psychiatric Institutions for the Commitment of Political Dissenters. I was one of its four members.

For me, the Russian cases, if authentic, were only extreme and outrageous practices which illuminate problems which may exist here at home. I saw no point in condemning the Russians without some simultaneous examination of the potential for similar abuse in this country in, for instance, state, military and penal institutions. This is what I told the APA and, happily from my point of view, the Board of Trustees agreed. The term of the Ad Hoc Committee has been extended for one year, expressly to engage in critical self-examination which at this date includes some hard-nosed research into the conflicts which beset a psychiatrist when his master is other than the patient he treats. Such a response is courageous rather than angry and defensive, and there is some potential for change in a study of whether conflicts of interest lead to abuses of medical judgment at the patient's expense.

Many similar conflicts must also beset you who serve several masters. Don't the wishes of parents influence your decision to treat or release a mentally retarded child? Doesn't fear of repercussion from higher authorities or an outraged public compromise your independence in deciding to release patients in order to allow them to take the risks of freedom?

I think you can and must devise ways to bring these conflicts to the surface, perhaps through periodic professional review and discussion of admission, treatment and release decisions. Or through a decision

to set a maximum length to every involuntary commitment, at the expiration of which the treatability of the patient must be determined, and perhaps a new disposition recommended. I find this an intriguing idea which certainly merits further study, especially by you.

As long as you -- and I mean all of you: the MD's, the PhD's, the administrators, the psychiatric nurses, social workers, physical therapists and aides -- as long as you remain silent about these questions, no one else will soon raise them, and people will be abandoned, perhaps forever, in the bowels of your hospitals, your clinics, your offices and your schools. All of you who touch the lives of the people in your treatment programs are deceiving not only the patients, but all of us who are relying on you in the first instance to tell us at least what you cannot do.

As long as you quietly go through the motions of all the administrative procedures, the reams of red tape and the endless meetings which any elaborate bureaucracy seems to require, you are also performing the janitorial function of sweeping society's problem under the hospital or institutional rug. I think you have higher aspirations. But even if you do not, you at least have to live with yourselves and take responsibility for your own actions. Please don't misunderstand me. I am not asking you to accept the guilt for all of the abuses which our failure to examine the right to treatment has allowed to exist up to now. It has taken us this long to even face the human garbage heaps we have created. But I do consider you guilty if you continue to be silent about current abuse. If you don't want to be held responsible for turning hospitals or training schools into prisons and garbage pits, then tell us now if that is happening. Have the courage to send right back to us the people we have tried to sweep under your rug.

I hope you will not respond to these comments on your professional activities with feelings which will block out any merit they might contain.

Not too long ago I was invited to speak to the American Association of Correctional Psychologists' Conference on "Psychology's Roles and Contributions in Problems of Crime, Delinquency and Corrections." The substance of my address was to query the unexamined premise of the entire conference: Does psychology have a role in the field of corrections? Although I stated there was not much evidence, I didn't try to tell those professionals whether it does or not. I did urge them to examine themselves the wisdom of confining their expertise to the problems of crimes which have already been committed. Instead of responding in any fashion to this question, the Association practically apologized to its members for such an unwanted intrusion.

Some of you may also have heard or read about the preliminary reports of a study of the psychiatric profession organized by Ralph Nader. These reports charge that while psychiatrists are eager to apply their expertise to a wide range of intriguing societal problems, they are leaving untreated the real medically sick people in

our country, defined by the report as "the mentally disabled, the severe brain dysfunctions, severe psychosomatic disorders, metabolic deviations, and perinatal trauma." The study is particularly critical of the training and research policies of the National Institute of Mental Health, and of how these policies are politicized by the current administration and largely ignored by the Congress.

Although it is too early to take the true measure of psychiatrists' responses to these charges, one of the initial volleys came from a truly distinguished Yale professor who seemed to dismiss the Nader group as "naive." In reference to the report's principal author, a 1971 graduate of Harvard, this psychiatrist wrote: "I doubt very much that it would be useful to send a first-year medical student to review the policies, functioning and administrative efficiency of the Department of State." I am not so sure!

I do not have to buy, or even remotely agree, with the Nader report to know that its real merits do not turn on the age and credentials of its author. Despite any substantial defects which the report may contain, the crucial response is not to attack the Nader group but to begin to confront the intertwining moral, legal and medical questions which such a study may pose.

There are, after all, problems which require societal and moral judgments beyond the scope of a single profession's expertise. Such problems continually confront the medical profession. Faced with limited resources, for instance, should we spend thousands of dollars on a few renal dialysis units in order to save life, or is that money better spent in furnishing dental care to thousands of children who might otherwise never see a dentist? No matter how you come out of this kind of question, I doubt whether you would feel comfortable leaving the decision to either kidney or dental specialists.

Your work poses similar complex value judgments. Do you alone have the right or the ability to decide what to do with people who were committed to a hospital because they were dangerous to others, but whom you cannot treat? Do you want the responsibility of locking these people away and maintaining the myth that they are treatable?

We have established legal processes for resolving decisions which require the accommodation and reconciliation of many competing value systems, all of which point to different solutions. Some groups might insist we lock up ALL arguably dangerous people and admit this is preventive detention. Others might advocate drastic behavior modification, or attempts to provide still more treatment alternatives. Still others might want to take the chance on releasing many of these patients because they believe the values of freedom and liberty count for alot.

Once you see how complex these problems are, you should help to bring them out of the doctor's office and into the courtroom or other legal arena. You are an essential part of any process which makes decisions about treatment for the mentally handicapped, and

your input is critical. You can generate the thrust of reform by complaining about its inadequacies.

For despite my more desperate moments, I still believe that the judicial process is an important tool for reform. You should not fear it, since it is your tool. Neither should you think that a judicial decision is instant revolution. It is not. The history of the right to treatment decisions should convince you of that.

Perhaps, I am asking too much of you. The kind of reexamination of our right and our ability to treat the mentally handicapped which I am urging could get you into serious trouble with your superiors. Or, it may lead you to the conclusion that your function and your job are really part of the problem, rather than the solution. I realize that these are grim alternatives. It was pointed out to me at a meeting in a large state hospital in California that here I am, in a life-tenured position, without Sacramento peering over my shoulder. Unfortunately, the only real alternative I see to speaking out is the pretense that there is nothing wrong with the right to treatment. I have become too sensitized to the many problems in the enforcement of such a right to remain silent.

It would be a great mistake to ignore the impact of the Wyatt decision, and to leave undone the reforms it requires. It would also be a great mistake to think that Wyatt is the end of the road. We have not even set foot on the path of grappling with the fundamental problems. As I said, I cannot promise you that starting down that path will bring you into the rose garden, but if you can shove us in that direction, at least there is hope.

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The Honorable David L. Bazelon is Chief Judge of the United States Court of Appeals for the District of Columbia Circuit. He is an eminent juror, has been active in the area of the mentally handicapped and the law for a number of years and served on the President's Panel on Mental Retardation which reported to President Kennedy in October, 1962. In 1954, Judge Bazelon wrote the famous "Durham Rule" for insanity defense which was revised in the 1972 "Archie Brawner Case" before the U.S. Court of Appeals for the District of Columbia.

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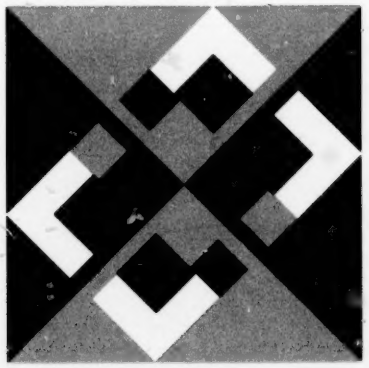

THE RIGHTS OF THE MENTALLY HANDICAPPED: THE ADMINISTRATOR'S PERSPECTIVE

The Implications of Recent Litigation Involving the Rights of the Mentally Retarded

Robert M. Gettings

I. BACKGROUND

When Sam Ornstein originally asked me to speak to you, he said "Bob, would you be willing to give a review of the various court suits all around the country?" I said, "yes." But, to be frank, Sam and his cohorts have done such an excellent job of getting speakers who have been involved very directly with the suits that it would be presumptuous of me to attempt to tell you, from my perspective, about the Alabama suit or the Pennsylvania case, etc. So what I am going to try to do is look at some of the implications of the present court suits. What do they really mean to a person who has program responsibility in the state?

Certainly within the past year we have seen a rash of suits filed in the federal district courts across the country which involve the constitutional rights of the mentally retarded - right to treatment, right to a free public education, and freedom from involuntary servitude. The programmatic implications of these suits are so sweeping that they promise to shake the very foundations of our traditional approaches to delivery of services to retarded children and adults. I think many of us would agree that our approaches do need some shaking up. One can see the potential implications of these suits already in the rulings of the courts in Alabama and Pennsylvania. Clearly this recent litigation has profound meaning for all of us. It is not simply a scattered or temporary phenomenon, but part of a broader trend in judicial thinking which stresses a more active role for the courts. Because of the basic constitutional rights involved and because of the favorable responses of the courts thus far, I think it is safe to predict that we are going to see many similar suits in the near future. In fact, if you read carefully the testimony in the Alabama case, and the Pennsylvania case as well, what was said was that these states weren't atypical examples of institutional or educational programs, but rather common examples of some of the things we see happening all across the country in programs for the retarded.

II. ISSUES INVOLVED IN THE SUITS

We might categorize the suits in three types: (1) the right to treatment which probably most of us are aware of and concerned about; (2) right to education; and (3) freedom from involuntary servitude.

The litigants in the right to treatment suits are claiming that mentally retarded residents in publicly operated institutions have a basic constitutional right to adequate treatment and habilitation

services and that denial of this right should be interpreted as a major breach of the resident's entitlements under the 14th Amendment to the United States Constitution; also it has been argued in some of the cases that lack of public funds should not be a constitutionally adequate excuse for denying rights to retarded residents.

As Judge Bazelon so eloquently stated, in the Alabama case the court has displayed a willingness to take extraordinary steps to protect the rights of retarded residents in Partlow State School and Hospital, including the establishment of detailed minimum program standards for the operation of that institution. The court also has directed the state to take several other specific administrative steps in an effort to operate adequate services and facilities. No, I am not going to reiterate the details of the Alabama case. You know that somewhat similar relief is now being sought by claimants in cases involving the Willowbrook State School in New York State, Belchertown State School in Massachusetts, and also a series of mental health and mental retardation institutions in the state of Georgia.

The second broad category of suits we might talk about are the "right to education" suits. Certainly the ruling in the Pennsylvania case suggests that no retarded child, regardless of the degree or severity of his handicap, may be denied access to free public education geared to his own particular needs. Abridgement of this right, the court says, is clearly in conflict with the equal protection clause of the 14th Amendment to the United States Constitution.

In the Pennsylvania case the courts appointed two masters to oversee the implementation of the agreement and laid down a timetable for assuring that every eligible retarded child is enrolled in public education programs. Similar relief is presently being sought in the District of Columbia courts.

The third broad category of suits is what I will call the right of freedom from involuntary servitude. Petitioners in the case that is now pending before the federal courts in Tennessee are attempting to establish the principle that no resident may be required to perform services for a facility against his will or without compensation for his labor. They say that to require an institutional resident to work without pay or for substandard wages constitutes peonage in violation of the prohibition against slavery contained in the 13th Amendment to the United States Constitution and also in violation of minimum wage standards laid down in the Fair Labor Standards Act, as amended in 1966.

So these, in very broad general terms, are the kinds of issues that we are talking about when we discuss rights suits today.

III. IMPLICATIONS OF RECENT LITIGATION

Let me now turn to some of the implications I can see in these suits. I think as we read between the lines, we can find several common threads running through the current court actions. First of all, it seems to me that parents and other consumers of services are displaying a new sense of militancy towards the substandard conditions which continue to exist in the state residential facilities and public school classrooms alike. They are frankly fed up with our old approach of incremental change, and are increasingly turning to the federal courts for relief.

Second, a closely related issue is that people are beginning to say charity is no longer good enough for what we are talking about in terms of the mentally retarded. The retarded have certain rights as citizens, and they should receive the benefits attendant to those rights as a basic constitutional entitlement.

Third, one can draw a parallel between this new rights movement and efforts to protect the civil rights of black people. Many of the principles that were enunciated in the great civil rights decisions of the 1950's and 1960's had applicability, if you will, to other minority groups including the handicapped. I think that if you look at the origins and judicial philosophy involved in the recent cases involving the mentally retarded, you'll find that they have many parallels to the great civil rights decisions. Consumers, aided by a new breed of public interest lawyers, are beginning to say, "You know, we're tired of sitting in the back of the bus when it comes to getting services for our children. We want our rights and we want them now."

The fourth thing you might look at is that the federal courts are showing a great deal more willingness to delve into areas which previously were considered strictly administrative domain. As indicated before in both the Alabama and Pennsylvania decisions, the courts strongly exercised judicial authority in outlining specific administrative steps which must be taken to correct program deficits. Not many years ago these actions would have been considered an unconstitutional encroachment on the prerogatives of the executive branch of government.

Fifth, I think we have to say that the past failure - and let us call it that - of professionals to find meaningful solutions to the problems of many retarded individuals, has created an atmosphere of doubt and suspicion among consumers and society in general. They are saying, "Look, you've asked us to trust your professional judgment. We did and look at the kind of mess you've gotten us into."

This reaction is not limited to the field of mental retardation, but rather tends to permeate the whole area of human services today. I believe this factor is very much in operation in some of the cases. You don't have to look beyond the very detailed program

standards the court laid down in the Alabama case, or the appointment of masters to oversee implementation of the court's ruling, the naming of human rights committees, etc. The implication is clear, I think: Professionals are not to be fully trusted.

Finally, I think that the courts are redirecting our attention to the rights and prerogatives of the individual and what he derives from our service programs. Because of the very nature of judicial thinking, courts are inclined to view problems from the standpoint of the legal entitlements of the individual. From my point of view, this perspective is providing a very healthy counterbalance to the view of many budget officials, legislators, and programmers who prefer to look at things in terms of service groupings rather than focusing on what happens to the individual.

IV. ADMINISTRATIVE PROBLEMS SURROUNDING THE IMPLEMENTATION OF RECENT COURT DECISIONS

Let me turn now to some of the administrative problems which I can see in terms of implementing some of the court decisions. Judge Bazelon was quite right when he indicated that the court's decision is only the first step in a very long road we are going to have to go down in terms of bringing about real change in our field. The recent flurry of litigation in federal courts has caught most leaders in the field of mental retardation unprepared. The courts, on the other hand, possess no special expertise and have to depend on the advice and counsel of qualified professionals - particularly when it comes to the development of program standards and implementation strategy.

Obviously, any program guidelines which are enunciated by the court, without the active involvement and backing of knowledgeable experts, promise to be unworkable.

Apparently much of the expert counsel received by the courts in the Alabama and Pennsylvania cases was rather hastily developed by a relatively few number of individuals. Now, I certainly understand that this rather makeshift procedure was necessitated by the unprecedented nature of the cases, and also by the time frame in which they were forced to work. However, it seems to me that as we proceed, we want to develop more rational and well thought out procedures for presenting expert opinions to the courts. Even some of the individuals who were most instrumental in convincing the court to take action in the Alabama and Pennsylvania cases are beginning to question the process by which the courts reached their opinions and the adequacy of procedures and mechanisms for implementing these court decisions. While still strongly defending the need for legal intervention, they are concerned about developing more effective methods for effectuating the actions which the courts are desiring to create. I think a few of the decisions reached in the Alabama case tend to point out the need for the

courts to have access to adequate program counsel, which represents a broad consensus of opinion in the field.

For example, even if one accepts the fact that additional ward attendants were needed at the Partlow State School and Hospital, one might seriously question the wisdom of the court's action in directing the state to hire 300 additional workers in a period of 30 days.

Are the long-range program needs of the residents at Partlow best served by such precipitous action? Or would it be better to phase such staff increases over a somewhat longer period of time so that adequate provision could be made for initial training and proper supervisory support?

In raising these questions, I am not being critical of the court. I recognize that they saw a very serious kind of situation that they considered to be of an emergency nature. At the same time, we find in our institutional settings that it is not just the residents we are trying to institutionalize, it is the staff also. Without the proper indoctrination into what you want them to do and how you want to change the pattern of service, there is a real threat that in bringing new people on so fast you will create a very unhealthy situation.

Another example of the unforeseen administrative problems which I think would be created by the court's decision is the directive concerning transfer of patients whose parents are non-residents of Alabama. In issuing this ruling, the court apparently took no real congnizance of the Interstate Compact on Mental Health which, over the past twenty years, has developed an orderly method for transferring institutional residents across state boundaries. Obviously, if any state would begin to dump indiscriminately all out-of-state residents, the spirit of this very useful Interstate Compact would be destroyed.

I believe that the central issue in the pending cases is, "How far should the courts go in defining the specific program standards for adequate treatment, education and habilitation?" Clearly, institutional residents deserve the full protection the courts have to offer. Few would deny that many residents have been refused access to habilitative programs in the past, and certainly today, the court intervention is a very helpful tool.

On the other hand, there is a thin line between the proper exercise of judicial authority and encroachment on the legitimate prerogatives of the administrator. The latter situation can stifle the proper exercise of administrative initiative by substituting judicial opinion for executive direction. In the final analysis the success or failure of any public program is going to rest with the responsible governmental officials. The courts can and should intervene to protect the individual's interests as a citizen; however, in doing so they should not tie the hands of responsible administrative officials, since the ultimate and almost inevitable results will not be in the best interest of the patient.

V. CONCLUSION

In conclusion, then, I think it goes without saying that the recent court decisions hold rather profound implications for every director or coordinator of state programs for the mentally retarded and also directors of programs for the mentally ill. Certainly the new activist role of the courts has added a new dimension to an already complex array of problems facing state mental retardation agencies and superintendents of the institutions as well.

However, if I can leave one point with you, I think it is this - rather than taking a negative or defensive position, we might ask ourselves, "How can the new role of the courts be molded into a positive force for change within our field and how can we as program administrators reinforce the broad goals the courts are beginning to enunciate?"

Certainly the kind of role the courts are articulating in the Wyatt decision and the Pennsylvania case are things that we, as program people, have argued in favor of for many, many years. The great challenge that lies before those of us at this meeting today, then, is to deal with this issue of where we move from here in terms of helping the courts and in terms of preparing ourselves internally to meet the challenge of legal action. You know, eventually it should not be necessary for us to go through the time consuming and burdensome route of litigation to accomplish these kinds of goals that we have all sought for so long.

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Robert M. Gettings is Executive Director of the National Association of Coordinators of State Programs for the Mentally Retarded, Inc., a private non-profit organization devoted to improved and expanded public services to mentally retarded children and adults.

Yesterday, Today, Tomorrow: A State Program Official's Viewpoint

David B. Ray, Jr.

I. The Past

Fifteen short years ago, before the advent of Ralph Nader's Raiders and the civil rights movement, those of us working in the field of the handicapped were "God." Parents were thankful for our help and were just as pleased when we threw them a morsel of bread. Citizens would turn to us and say, "Oh, it's wonderful that you are working in such a worthy cause to help those unfortunate people." At that time we could stand before the state legislature and "play our violin" and pass the hat and get money for services for the retarded or the handicapped without accountability. There were few services, little funding, and in many ways it was a much simpler life - particularly for the professionals. There was very little involvement from the federal government. For example, there was no such thing as Title IVA, Title XIV, developmental disabilities, child development legislation, OEO, law enforcement assistance grants, etc. However, it was a more complex existence for the people we were serving, because there was little coordination.

If you operated an institution for the retarded, you didn't worry too much about individual differences. You were not too interested at that point in time in moving those individuals out. It was a matter of just maintaining a program.

A superintendent was a king, and could stay a king for a long time. If he could mend his political fences, mind the store, and keep scandal down, he had it made.

It was a peaceful existence. We were kings and we were gods and what we said went as far as the person we were trying to serve. We could have a committee meeting and decide this is what is going to be done with this child and no one argued the point - not the parent, not the consumer, and not the staff. They didn't argue because we were kings and we were gods.

And in this life we felt content, snug and sort of like martyrs. We felt that we were revolutionists because we were not running the snake pits of the past; we were treating the kids well; we were keeping them out of society's way. In our snug ways, we were like knights on white horses. We were carrying the banner. Yes, one fleeting look back - what a simple life; what an uncomplicated life.

II. The Present

But today, running an institution is a complicated, often frustrating experience. It is far from a simple life. Things have changed. Ralph Nader's Raiders are here. The civil rights movement is in full swing. Women's lib is booming and now we are finally getting around to talking about human services for the handicapped. I heard one speaker recently say that life used to be simple for the professional and more complicated for the consumer and the parent, but that the roles are now reversing. With the complexity now shifting to the professional, hopefully, it will be a more simple life for the persons we are trying to serve.

Today, parents and consumers take a more active interest in what we, as professionals, recommend for their children. Today, even the most junior members of the professional team speak out more vocally on what they think is best for the individual. The man on the street, television stations and the newspapers take a more active role in awakening state legislatures and the United States Congress to the needs of the retarded and handicapped. No longer can we play the violin and pass the hat; the day of accountability is upon us.

It is doubly complicated with the mass of federal funds and the seeming lack of coordination on the federal and state levels. Dr. Darrel Mase from Florida has indicated that 61 different federal agencies give grants in the field of manpower and manpower training. Look at where mental retardation is located in federal government. What programs relate to the retarded? Think right now in your own state of the different agencies that have some responsibility in the field of mental retardation.

So, it is complicated; it is frustrating; and it is challenging. It is challenging because it is a new day for the mentally retarded. It is challenging that we are now moving towards the human service model. We have heard discussions over the years of medical models and non-medical models, but I give to you the human service model.

There is a change in the residential picture also. It is just one of the many types of services that are needed. We are seeing in the institutions the "in and out" concept of short-term care. The full array of community services are being used to build programs for the retarded where they live. We are starting to see the development of advocate systems and ongoing evaluation efforts. The retarded and the handicapped are living and participating in the community, in employment, in recreation and in religion.

Many professionals have been able to bridge this gap between how it was and how it is. Many others have either fallen by

the wayside or are living in a situation that is intolerable for them and their programs.

So now, in this changing system, we have to look at the way the present bureaucratic system is operating and the issues which we, as professional administrators, must face today. One of these problems is the rigidity of the bureaucratic process. It can hurt us, as can the civil service system, even though it is a great protector. We need to protect the rights of the employee but it is hard to get rid of people who do not produce, whether it be a secretary or a worker on a ward.

We face the rigidity of disciplines - The M.D., the psychologist, the social worker, or the educator who sees his role in such a narrow way. He has been trained that way and, understandably, he tends to react that way.

The building of empires seems to be the thing to do in this country. We all want to be successful. I want to have a good M.R. system in Tennessee. The superintendent wants to have the best institution. And this is good. But when we build empires, I'm afraid we are going to face a taxpayers' revolt. I think we are seeing it now in the way the people are voting against the system - a social system that is bigger than what we are talking about today.

We have, in so many cases, programs that are tied to buildings. We build a building and our program becomes wedded to it. I find this so true in my institutions in Tennessee.

We have facing us as professional administrators today the changing patterns in services to human beings; we are beginning to look at the whole individual and not just the mental retardation. We see this in the new Developmental Disabilities Service Act, which may be a signpost of the future.

Another area is accountability - the evaluation or service program audit. For many years we have audited books, but we have not audited what we do to human beings. Is what we are doing good or bad?

I say to you administrators, "Do not do your own audit." The bank does not hire auditors on its payroll; they bring them in from outside. We must bring outside program auditors in to look at our program for objective results.

There is a gray area in considering the rights of the retarded. For example, in Tennessee, as we move individuals out of the institution, we are faced with a lawsuit. Individuals were moved out into low-rent apartments. Some people were critical because people were placed out in these apartments. What about

the areas where they need supervision? When you exceed that supervision are you making them slaves? When you do not give the retarded enough supervision, are you falling down in protecting their rights?

The manner in which we administer discipline in the institutions - behavior modification and the use of restraints - came out very strongly in the Alabama suit. It gets back to the fallacy of the adage, "Because I am a professional, I am God." What are we changing behavior for? What is the real goal? Are we doing that because it makes us feel better?

Another role is the relationship between the professional and the lawyer. Personally, I am less interested as a professional in developing techniques and mechanisms in Tennessee to keep from having lawsuits. I am more interested in developing sound programs for the people that we serve. As professionals in Tennessee, we say let us keep our eye on the client, on the resident, and on the human being, and lawsuits will take care of themselves. We cannot run scared all the time or we will never be progressive.

I think we are on dangerous ground in this country (even though we just signed a super-contract with the Welfare Department on Titles IVA and XIV) by allowing money to dictate our priorities. I remember one time in a particular state that I was visiting where a group of people got together and were going to plan future strategy. But their first question was, "Where is the money in the federal government?" When they found that out, the fundable area automatically became their priorities. We have got to have our programmatic priorities first and then sell the powers that be, to make these the government's priorities. I have some deep concerns that we are letting money dictate the directions that we are taking in this country in human services.

Another area is labor-management relations in the field of human services. This is a vital one and those of us that have been professionals in the field have had very little training in dealing with labor unions.

Another problem area for the professional, and particularly the administrator, is having a dream or a plan and then having it smashed because of inadequate advanced preparation. Consider the decentralization process. We have been preaching, "Let's decentralize our facilities in Tennessee." When I first came to Tennessee, some of the people, including parents, felt this was the approach we should take; but, when we put it into reality, some of these same parents became quite concerned. Do you know why? Because it might be their child that would leave the institution next. And even though they had been critical of the institution, it was a protection for them in the future. So we have a job to do when we have a dream

and want to sell it. Decentralization, by the way, causes concern for the institutional staff. They have fears that you are going to do them out of a job because you are going to do away with the institution. There can be a lot of unrest if you do not touch all bases.

There is also the problem many of us face of low attendant and aide salaries. Remember. The backbone of any institution is not the superintendent - he comes and goes. It is not the psychologist nor the medical doctor. It is the people on the wards and the people in the cottages. They are the backbone of the institution. They are with retarded people 18 to 24 hours a day. And yet, in Tennessee, the starting salary for aides is $330 a month. A supervisor for a building gets $420. This is a very serious problem.

Then the last one is one of my favorites - our failure to train administrators to be administrators. How do we choose administrators in this country? In most states, if you happen to have an M.D. behind your name, or maybe a Ph.D., "That is the guy, let's get him." You do not ask questions about what kind of administrator he is because to be a superintendent or a director of state M.R. programs you need professional background. Yet, 85 or 95 percent of your time will be spent on administrative matters: lawsuits; labor-management relations; dealing with consumers; legislation; lobbying; trying to find money; and trying to settle intra-office squabbles. I do not think that we are taught that when we get our degree in education or medicine, etc. Fortunately, we changed the law in Tennessee this past year. Now you do not have to be an M.D., you have to have some experience in administration. But that by itself will not do it. I think that the key is teaching the administrators to be administrators of programs for human beings.

III. <u>The Future</u>.

In trying to look ahead, I am not bright enough to say what is coming, but I think we all know that we are moving away from categorical grants. This is a trend which you should be on the look out for since it could cause you some problems.

The other program is the Developmental Disabilities legislation. I am not saying that the Developmental Disabilities Service Act is bad; I am just saying that as you look ahead, think about the implications of this legislation and the "umbrella approach" for reorganization of state government. I think some states have undergone or are in the process of human service reorganization. What is the right structure to organize state and local services for the retarded?

I feel there is a tremendous role developing for the "advocate", both tax supported and non-tax supported. I have seen some grants funded on the federal level for the advocate who works in the Governor's office. I think Oregon and Washington have had such programs for a couple of years. I have often thought that if we have an advocate that is tax supported, he cannot be a true advocate; so you need his counterpart, who is non-tax supported, both on the state and local level, to be a true advocate.

One item which we are trying to implement, with the permission of the Office of the Attorney General in Tennessee, is having attorneys on the staffs of the institutions for the retarded and the mental hospitals. I think he will rule in the affirmative. It has been denied in the past, but I would like to see these people being tied in to our professional staffs and to have strong liaison with the Office of the Attorney General. I think we need attorneys on the staffs of central offices as well as the institutions for the retarded and the mentally ill.

The role of universities and other institutions of higher learning in training professional people for human service delivery must change. We need new breeds of personnel.

I believe there is a role for the private sector in furnishing services to the retarded. Part-time brain power can be obtained through a purchase of service agreement. It is difficult to get full-time professionals on the salaries that we pay in state government, particularly in Tennessee. Sometimes part-time brain power, whether it be legal or medical, can be an excellent supplement.

Then, I think that we will move toward having a type of Food and Drug Administration for educational materials which tests out learning materials before they are used with human beings. Right now you can advertise a teaching machine or curriculum material in a CEC or AAMD publication. Almost anyone can buy space. People can order these gadgets and maybe it will not kill them, as a drug might, but we might be doing something that is going to hinder their progress in the future from a behavioral standpoint.

And, finally, I think we need to cross state lines to deliver effective services. Tennessee is a good example. Memphis, Tennessee relates almost as closely to parts of Arkansas and Mississippi as it does to Tennessee. Why not consider service catchment areas in terms of natural areas of business and commerce?

In closing, I hope the day will come in the not too distant future when parents who have handicapped children will have a

choice of services and it will be the best service that is available for their child at any given time. I think this is a challenge that we face on all levels.

I would like to be able to say to you today, but I cannot, that there will be no institutions for the mentally retarded; but I hope that I can say to you that there will be a new type of residential facility. There will be less quantity and more quality. It will be an integrated part of the communities in which we all live.

Most of us say in our requests to the legislature for money that mental retardation is a complex subject - that it is medical, educational, social, psychological, vocational, etc. I hope the day will come, regardless of where the programs are located, that the educational parts of services and programs will be operated by the educational agency; that the social parts of a program will be operated by the people who are experts in social services; that rehabilitation is furnished by the rehabilitation agency; that health and medical services are furnished by that unit of state or local government which has these responsibilities.

How do you put these elements together? You put them together by hiring a manager who has as his goal the human being and not the building of an empire. In saying this, I see a fuller umbrella of services for human beings that will be organized in this country. And I see an advocacy system, especially for those children who do not have parents. The advocate will represent that individual when decisions are made which affect him, whether it be placement in the community, sterilization or his ability to marry and live a human life of dignity in the community.

As I look back at how it was and how it is now, the issues that we face are really the challenges of tomorrow. Personally, I feel these are exciting times. I do not really look on lawsuits with fear or resentment. I do not look on the unrest that we are facing today, whether we be professionals or parents, legislators or private citizens, as totally frustrating and depressing. But, I look on it as a challenge in this country to change the system that applies to human beings. I think the basis of all the trouble is that we have a 1930 era delivery system trying to provide services in the 1970's, and, in most cases, we are not, at this point, even heading in the right direction. We have an opportunity, for the first time, to come up with a step by step plan on where we are going in human services. We can set the priorities, develop the methods of financing and even conceive ways of selling the plan to the public. In essence, I feel real progress can only come about when this nation puts into practice the following - "Human beings are our number one priority" - and backs up this societal priority with the money and the know-how to do the job.

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Mr. David B. Ray, Jr. is presently Assistant Commissioner for Mental Retardation, Tennessee Department of Mental Health. From 1965 to 1970, he was the Executive Director of the President's Committee on Mental Retardation. Mr. Ray has held many administrative and management positions in the field of mental retardation over the past two decades.

Rights Litigation - A View from the Private Sector

Philip Roos, Ph.D.

Unlike many other animals, man does not abandon his handicapped offspring. Rather he shelters him, hopes for him, dreams for him, and loves him. Some 20 or 25 years ago the associations for handicapped children were just beginning to develop. Let me share with you, so that you can better understand this movement, the factors which led to the development of these associations. Essentially, there were five. Very simply, the forces operating at that time to generate this movement were the following: (1) professional neglect; (2) professional mishandling; (3) lack of community services for the mentally retarded; (4) popular concern for institutions; and (5) the beginning of hope generated by scientific advances and discoveries.

The National Association for Retarded Children (NARC) is often characterized as a national voluntary health agency. It is not. It differs significantly from voluntary national health agencies on at least three points:

(1) It was started by parents, rather than by professionals. Most of the voluntary health agencies were started by professionals, particularly physicians.

(2) NARC encourages members' participation. It is a decentralized organization which shares leadership. The local and state associations are the backbone of the movement.

(3) Health, per se, is not necessarily the primary focus of the Association; as a matter of fact, usually it is of secondary importance.

After twenty odd years of the Association's existence, we find that many of the sources of frustration that generated the movement are still very much with us. For example, parents of retarded children are still exposed to professional mishandling. As a specific example of what I mean by professional mishandling, let me mention the most obvious, and, I feel, the most widespread -namely, rampant ignorance. Most professionals are still grossly naive about the field of mental retardation, and surprisingly this is even true of such specialties as psychiatry, obstetrics and pediatrics.

I need not bore you with the detailed evidence relative to the totally absurd and unbelievable conditions that still exist in our residential facilities today because many of you are familiar with these situations from first-hand experience.

In the area of education, NARC last year conducted a national survey and found that only 36 percent of retarded children of school age

were getting any educational services. In some parts of our country, less than 15 percent of such children have access to educational facilities. It is not surprising, then, to find that some 2 million retarded men and women who have the potential for being productive citizens are unemployed and living essentially parasitic existences. The tragedy is that today we are generating the conditions that will breed another generation of retarded men and women without training, without preparation and without education; and they, too, will live parasitic existences.

A sure source of frustration to which you have already alluded is the whole problem of stigmatizing and labeling, and what is worse, mislabeling, and thereby predetermining the destinies of the individuals so labeled. Note the terms which we still use: educable; trainable; sub-trainable; bedfast; non-ambulatory; and tube-fed. These very terms seal the individual's destiny. Once we label an individual as untrainable, for example, his chances of becoming educable are almost nil.

In spite of all these frustrations, the last decade has witnessed a growing rapprochement between professionals and parents of retarded children. We are, indeed, witnessing some rather surprising alliances between the two groups. These can be traced to a number of factors. For example, there is evidence that the professional and the consumer are striving for common goals. There is increasing overlapping membership in organizations. We found, for example, that 25 percent of the members of NARC were professionals in the field of mental retardation. Professionals often join the consumers. This is equally true in the formation of coalitions, often aimed at joint legislative efforts. NARC, for example, has formed a coalition in Washington which addresses itself to various legislative issues. Included in this coalition are the National Association of Coordinators of State Programs for the Mentally Retarded, the National Association of State Mental Health Program Directors, the American Association on Mental Deficiency and the Council for Exceptional Children.

At the same time, we have witnessed the growth of institutional parent groups, groups similar to ARC's but developed around institutions, much as PTA's do around educational systems. These institutional groups have frequently become strong advocates of the institutional administration and have protected the professionals against attacks and criticisms. We have found, during the past few years, that professionals and consumers have joined forces to co-sponsor national projects of considerable magnitude. The development of the accreditation standards for facilities for the mentally retarded, for example, involved both NARC and AAMD, plus the American Psychiatric Association, CEC and the United Cerebral Palsy Associations - a new coalition of consumer and professional organizations.

The Developmental Disabilities Services Act, which was sponsored primarily by NARC, creates at the state and national level, an advisory and planning council which is composed of administrators, professionals and consumers.

NARC developed a grant proposal in concert with the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded. We drafted the proposal to develop a national training program for superintendents. This concept was so far advanced into the future and so foreign to the thinking of the federal establishment that, of course, we did not get it funded.

You might ask then, in view of this increasing harmony between the professional establishment and the consumer pool, "Why litigation?" I think there are some very excellent reasons why litigation is suddenly becoming a focal point of activity at this particular time in our history. Let me share some of these reasons with you:

(1) An important reason is strength. At long last the consumer has gained strength. He is gaining support. National policies and guidelines and international policies and guidelines are being developed. This is certainly true in the field of mental retardation; and, indeed, this is so generally true that the 1970's will no doubt go down in history as the age of the consumer.

(2) At the same time the consumer is developing expertise, he is becoming knowledgeable; he is becoming educated. Our own Association spends much of its time and very limited financial resources in educating its own constituents. The result is that the parent is now recognizing the fact that he and his child are being neglected. He is now recognizing the fact that the services with which he has been reasonably pleased in the past are, in fact, archaic, inappropriate and often destructive. The consumer is also learning that legislation may often be ineffective. It may be necessary, but unfortunately, it is not sufficient. Part of our survey of the educational situation last year reveals, for example, that there is no significant correlation between mandatory educational legislation and the number of persons who are actually being served by the educational systems of the various states.

(3) An important factor is that the consumer is beginning to lose his timidity. The parent is less in fear of retaliation; and let me assure you that the fear of retaliation has been a strong deterrent to action. I think we are seeing the fading of a great myth, the myth of professional omniscience: The concept that the professional knows and sees all and, if he really put his mind to it, could do all. The consumer is beginning to realize that the professional is almost as ignorant as the consumer himself.

There has also been a shift in the orientation of many of the ARC groups over the land, a shift from the concept of providing services, to the concept of obtaining services. This means that more and more of the ARC's are assuming the role of advocate and the role of monitor. Rather than trying to run a half-baked workshop, day care center or pre-school program, efforts are now being directed

to insuring that the government operates these services. The function of the ARC is becoming one of quality control, of monitoring, of being an advocate.

Perhaps one of the most potent factors leading to litigation is the factor of impatience. It is this dimension, I think, which most clearly differentiates the administrator from the consumer today. They share the same goals, but the consumer feels, "I cannot afford to wait. This is my child. Every day is precious." The consumer is dissatisfied with past solutions. The research psychologist who studies sensation and perception uses the term "J.N.D." -- a just noticeable difference. The advances of many programs have been in terms of "J.N.D.'s" - just noticeable differences, a 5 percent escalation in budget for the Division of Developmental Disabilities this year. Well, by damn, a "J.N.D." is not adequate when we are dealing with human beings, and it is here that the consumer is becoming most concerned. The consumer is also insisting on a realignment of priorities. Priorities which reflect the dedication to individual dignity on which this nation is founded.

Even in spite of all of these considerations, we do not feel that litigation is the strategy of choice. In order of preference, we feel that: (1) change can be catalyzed by cooperation with program administrators. It is in this arena that we would hope to make the greatest change, through joint cooperative action. (2) If this fails, then we would seek cooperation with the agency and/or state level administrator who is responsible for the program. (3) The next step would be legislation. (4) Only when legislation fails, would we turn to litigation. In point of fact, unfortunately legislation has failed in too many cases.

To conclude, ladies and gentlemen, administrators should recognize that, for the consumer, the time for pleading and for begging has passed. This is the time for demanding human rights.

I feel that professionals, administrators, and legislators all generally share the consumers' goals as well as the consumers' frustrations. I feel confident that they will act to translate dreams into realities. In those cases, and I am sure they will be rare, where the retarded person's right to humanity continues to be procrastinated, we are now ready to turn to the courts. The time for justice at long last is now.

* * * * *

Since 1969, Dr. Philip Roos has been the Executive Director of the National Association for Retarded Children. From 1967 to 1969, he was the Associate Commissioner of Mental Retardation in New York. Dr. Roos was also the Superintendent of Austin State School, Austin, Texas from 1963 to 1967.

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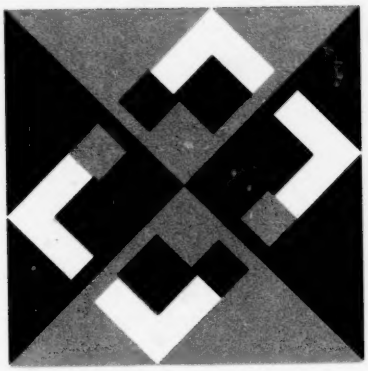

THE RIGHTS OF THE MENTALLY HANDICAPPED:

THE ATTORNEY'S PERSPECTIVE

National Council on the Rights of the Mentally Impaired

Bruce Ennis

How many of you, prior to this conference, had ever heard of anything called the "National Council on the Rights of the Mentally Impaired?" One, two, three? That doesn't surprise me at all because it's only really been an ongoing organization since January of this year. We expect that it will become, in relation to the mentally impaired, an organization of similar impact to what the NAACP Legal Defense Fund has been to the civil rights movement. That's our goal. But even though this organization has only been around since January of this year, we already have a rather substantial docket of pending test case litigation. And the reason for this is that lawyers who are involved with the National Council on the Rights of the Mentally Impaired have themselves been working in this area for several years. The interesting thing that you may not be aware of is that this conference is part of a response to a flurry of test case litigation on behalf of the mentally impaired.

Most of that litigation has been handled by only a handful of lawyers, maybe 60 percent of whom are in this room today. The mental illness and mental retardation bar of lawyers in this country is just a tiny segment of the legal profession. Most lawyers know nothing at all about this area and probably do more harm in bringing test case litigation to the persons they are ostensibly seeking to serve, than if they had stayed out of it altogether. That is one of the reasons we formed this National Council. Lawyers around the country are now starting test case litigation, some of it ill-founded and ill-prepared. It is our hope to serve as an umbrella organization to coordinate legal efforts around the country and to insure that the right cases are brought in the right states at the right time. What we cannot afford now is a court loss, something to set back the momentum of this ongoing movement. So far we have met with nothing but success, and if this meeting were held a month from now, maybe we could report even more to you.

Let me describe very briefly to you some of the cases that we now have pending in court. One of them, of course, is the Alabama case, the Wyatt vs. Stickney case you know so much about already. In that case three of the lawyers, Charles Halpern, Paul Friedman and myself, are lawyers of the National Council on the Rights of the Mentally Impaired.

Another case we have pending right now is the Willowbrook case for the retarded in New York State. In that case, a complaint has been filed; a very extensive pre-trial discovery has been conducted; and the judge has ordered a pre-trial conference to be held next Wednesday. So, I think by the end of next week I will be in a better position to tell you what is going to be happening at Willowbrook.

In response to this suit, the State of New York has already submitted depositions which we will evaluate. The Deputy Commissioner of Mental Hygiene admitted under oath that in response to this suit the state is now going to adopt the Accreditation Council for Facilities for the Mentally Retarded's standards for all of the state schools for the retarded in New York.

In another case, Dale vs. New York, we have sued the state for back pay and damages for a former mental patient who was forced to work in a state hospital. That would be an enormous step toward ending servitude. The state moved to dismiss the case, claiming that the work was therapeutic. The court denied that motion. It was appealed and the appeal was withdrawn. The case has been set for trial. It will be tried on Monday, June 26, 1972.

There are, in this audience right now, psychiatrists who are going to be testifying in that case saying that it was not therapeutic, and I am confident that we are going to recover a substantial amount of money for that woman. If we do, it will be the first time anywhere in the United States that a mental patient recovered monetary damages for the labor he or she was forced to perform in a mental institution. If we win that case, obviously there is going to be an enormous impetus for lawyers around the country to bring similar cases, because there are a lot of working residents and working mental patients. Some of those lawyers are going to be the lawyers who we describe as the cooperating attorneys for the American Civil Liberties Union. There are in this country approximately 15,000 lawyers who have signed up as being willing to devote a substantial amount of their time, on a voluntary basis, to work for the Civil Liberties Union bringing the kinds of cases that the Civil Liberties Board of Directors approves. Now the reason that that is important in context with this National Council, is that the National Council on the Rights of the Mentally Impaired is co-sponsored by three organizations. One of them is the American Civil Liberties Union (ACLU), another is the American Ortho-Psychiatric Association, of which Judge Bazelon is past president, and the third is the Center on Law and Social Policy, a public interest law reform group in Washington, D.C. in which Paul Friedman and Charles Halpern work.

Now, we are going to link up the National Council obviously with the ACLU lawyers around the country. One of the functions of the National Council will be to prepare model complaints, model briefs, model pre-trial interrogatories, model questions to be asked under oath of mental health officials, and send those around to all the ACLU affiliate lawyers so that when they start bringing these cases, and they will, they will have something to go on. The National Council will then serve as a backup center, flying around lawyers who have more experience in this area to assist in the actual trial of these cases. So right now, although there is only a handful of cases, I think it is fair to say that in two or three years from now it is going to be almost a deluge.

Another case the National Council is involved in is the case involving a woman who was involuntarily committed to a mental hospital and was immediately given substantial doses of tranquilizers and medication over her objections. Her objection was not only a personal objection but also a religious objection as she was a Christian Scientist who, therefore, did not believe in medication. We brought that case, again seeking monetary damages, against the Commissioner of Mental Hygiene and the hospital director. We lost in the district court but in the Second Circuit Court of Appeals, which is one of the most prestigious federal courts in the country, we won. The state appealed to the U.S. Supreme Court but the Supreme Court upheld our position and remanded the case to the district court to determine the exact amount of damages this woman should recover. What this case does, in effect, is open up the hospital door to the scrutiny of lawyers and judges about what goes on inside mental institutions. It was admitted, for purposes of that case, that that woman was lawfully hospitalized against her will. The point was that, even though lawfully hospitalized, she still retained her constitutional rights which had to be respected. And that even though the doctors acted in good faith, they had violated her constitutional rights. There will no doubt be other cases like that one which will be filed in the near future.

Do you see any difference in that case and a man committed to a prison? Are there any similarities? Would that same reasoning hold? Are prisoners going to be able to file for damages who work for 10¢ an hour for 20 years?

Mr. Ennis: You're talking about involuntary servitude. No, it will not because the 13th Amendment to the U.S. Constitution says that there shall be no involuntary servitude except as punishment for crime whereof the defendant has been duly convicted. So the Constitution specifically authorizes involuntary labor as punishment for conviction of a crime. Prisoners would not be able to bring that same sort of law suit. That would require a constitutional amendment.

Can you change that?

Mr. Ennis: All we are trying to do right now is to enforce the Constitution, not improve upon it.

I have been wondering about something for quite a long time. In Arizona, we have a statute that says if you are a danger to yourself or to others, you may be hospitalized, and we require the people to pay for their hospitalization. Has anyone ever brought a suit against that?

Mr. Ennis: Certainly, the National Council.

What is happening?

Mr. Ennis: We have won so far. We brought a case on behalf of a woman who was forced to pay for the cost of the involuntary hospitalization through a procedure which we attacked. We won the first step, which was to challenge the procedure by which she was forced to pay, and we won that in the Second Circuit Court of Appeals. The next step is to say, even if the procedure is fair, do they have to pay? We have a case pending on that right now, but there has been no decision by the court. That was a case! It's one of the most sympathetic cases to bring the issue up, because it was the case of a 21 year-old male college student who was involuntarily hospitalized over his objection and over the objections of his parents. He was hospitalized for three months, charged $90 a day, which was the prevailing rate in New York State receiving hospitals as of that time, and they billed his parents for the cost of his involuntary hospitalization. We are defending that case on the grounds that if he had gone out and bought a color television, his parents would not have to pay for that; if he had incurred other financial liabilities, his parents would not have to pay for those because he is an adult. So, I think there is a good chance of winning that, but the next step is to win it on behalf of the person himself.

It is interesting that in New York City, for example, which I am most familiar with, if you are committed to a psychiatric facility operated by the Department of Corrections, you do not have to pay for the cost of your psychiatric care; but if you are committed to a psychiatric facility operated by the Department of Mental Hygiene, you do. Some people are transferred back and forth between the two types of institutions by administrative order, they get the same type of services, and one week they do not pay and the next week they do.

George Dean just reminded me of something since involuntary servitude was mentioned. One of the things that the court ruled in the Wyatt case was that no patient or resident can be forced to perform any kind of labor that involves the operation and maintenance of the institution over his objection. If he volunteers to perform that kind of work, he must be paid the prevailing minimum wage and that once he has been paid the prevailing minimum wage, he keeps it. That wage cannot then be appropriated to pay for the costs of his hospital or school care.

Say a word about the newsletter and the service of disseminating information.

Mr. Ennis: As I have said, cases are springing up all around the country and the right hand does not know what the left hand is doing. One of the functions of this National Council will be to put out a newsletter to all lawyers and mental health professionals who are interested. It will keep everybody abreast of exactly what is going on around the country so that each of us can profit by each others' experiences.

Can you tell us where we can get this newsletter?

Mr. Ennis: Sure, you cannot get it; we have not started it yet. As I said, we just started in January of this year. We solicited funding from several foundations and received enough to hire two lawyers. Paul and Charles and I are working without salary at the present time. We have hired two salaried lawyers. We have not yet received enough funding from the foundations to start the newsletter, but we expect to get the amount we need in their fall board meetings. So, I would think we will start that later this fall. The National Council's headquarters will be at 1600 20th St., N.W., Washington, D.C.

On your comments on right to treatment and your statement on medication, what do you do in the case of the right to treatment of a child when the only way you can handle it is through medication and yet the child is a Christian Scientist.

Mr. Ennis: Well, I think the thing you have to do there is to disregard the fact of whether the person is a mental patient or not. If a person is sane and a Christian Scientist, that person can refuse medical treatment even if it is necessary to preserve that person's life. That is the ruling in the majority of the states. Now, should it make any difference if that person is mentally ill? Well, if the belief in the Christian Science religion, a membership in that religion, preceded the mental illness and is not a product of the mental illness - that is, if the person does not believe through hallucination that all of a sudden he or she is a Christian Scientist - then the results should be no different. That is what the superior court ruled. The role of the mental hospital physician in that case is not to determine what he thinks should be done, but to determine what the mental patient would have chosen for himself if mentally competent to do so.

What happens in the case of a retarded child, where there has been no previous condition and the parents are Christian Scientists? How do you determine whether the child is or not?

Mr. Ennis: That is an entirely different situation. Even when you are talking about the so-called mentally healthy, the courts have already made a clear distinction between the rights which the individual can exercise on his own behalf, and the rights which the parent can impose on his child. The Christian Scientist parent, in most jurisdictions, cannot prevent the administration of medication to his child on religious grounds. The court makes an individual determination in each case about what is best for the child. I think that is perfectly clear.

We have problems in retardation where parents will refuse an operation. They say, "The child is retarded, and I would just as soon he die from the results of the disease than for him to live."

Mr. Ennis: We are running into that right now in the Willowbrook law suit, and I think we are going to have to disregard the parental choice.

When you talk about child care, are you talking about all mentally retarded persons or are you talking about those under 21 or 18?

Mr. Ennis: That is such a sophisticated question that as lawyers we have not come close to defining when a person is a child for the purposes of the law. Some courts would say all mentally retarded persons are legally children; others may make a distinction on whether they are borderline, mild or moderate; others might make a distinction on their functional level. That is way in the future.

Dr. Gardipee: It's a very real question, because we are developing in California a program in which we are placing a lot of individuals in the community. We are having physicians in hospitals refuse to treat the adult retarded on the basis of informed consent. We do not want to have to take out guardianship, which we can do, on 40,000 retarded persons just to get a stitch put in an arm or leg, or something like that. This is a very real question.

Mr. Horowitz: We have just faced a particular lawsuit in the State of Washington in which a young girl reached the age of 18, the age of majority, and wanted out of the state institution. We had to come to the decision -- this is an adult. There was no valid court order placing her there. She is out and until a court, in an independent determination, decides that this person is so retarded as to be incompetent and appoints a guardian or somebody to act for her, I think it would have to be assumed that she is an adult once she has reached the age of majority. And I think that is the answer to your medical question.

We now have a law in California which, in essence, says that if anybody walking through a ward hears an adult patient say I want out, he has to help the patient fill out a writ which has the force of habeas corpus which must be reviewed by a superior court judge.

Mr. Ennis: We have a case on that issue pending right now in the U.S. Supreme Court, about whether the patient must himself take affirmative steps to demand release, or whether it must be automatic unless permanently waived.

Mr. Friedman: I would just like to make one point of clarification about the National Council. I am not sure whether it came up, but the call in the Rouse case that Judge Bazelon spoke of this morning was for cooperation between lawyers and mental health professionals. The problems we are talking about are medical, civil libertarian and legal as an interfaced problem and there must be cooperation.

I think Bruce's very quick description of a number of these cases, which were fairly carefully chosen in consultation with a lot of

concerned people to test issues, makes it sound a bit as if the National Council were coming after the superintendents and professionals and that we are out to get a lot of you. It is partly true, but not entirely.

The only point I wanted to make was that the National Council is officially sponsored by two legal organizations and only one interdisciplinary professional organization, the American Orthopsychiatric Association. We work very closely with a number of consumer membership groups in the field and mental health professional organizations. We have got formal liaison with the National Association of Mental Health, the American Psychological Association, and the Council for Exceptional Children. We have a very close informal liaison right now with the National Association for Retarded Children, the American Association on Mental Deficiency, and we will be developing working relationships, I hope, with other concerned consumer and professional membership groups in the area. We hope that the National Council will be a force for responsible cooperation and articulation of difficult issues and resolution of difficult conflicts; and then, we hope to be part of the process Judge Bazelon spoke of this morning by which the superintendents and other professionals working in the field can help bring out conflicts which are really too large to be resolved by one person, and which are difficult societal problems. We can use our legal system to help shape the basic principles and then the professionals and administrators can elaborate the rules and the regulations within an administrative law framework.

You mentioned the suit in Florida for damages against the hospital administrator and you talked about it as if the money had come out of the pocket of the physician who is not treating this individual. Now, in those situations where it is not the individual's own violation of hospital regulations, where he is doing the best he can, but where the legislature is not providing money or whatever, is that money going to come out of that doctor's pocket or is the state going to pay?

Mr. Ennis: We would never sue such a doctor for damages. The doctors we are suing in the Florida case, we have specifically alleged in the complaint, acted with personal malice and bad faith in withholding treatment from this patient whom they knew to be non-dangerous and whom they knew to be quite capable of living in the outside world. If we do not prove bad faith and malice, we will not get a penny in damages. We are not out just to go around and bring a flurry of lawsuits.

Mr. Horowitz: I happen to agree with the idea of the dollar method, and I would like to see some of the state legislators have to pay damages, because when you hit them in the pocket, they are going to start appropriating money instead of paying damage money.

Mr. Ennis: For example, without being too anecdotal, in the Florida case our client was told by a staff member at that hospital that if he could find someone on the outside to supervise him, to take custody of him as it were, he could be discharged. He did find such a person - a former college classmate of his, an accountant, a reputable man with a family who came down from New York State to Florida three times, signed agreements that he would take custody of our client, insure that he would receive out-patient psychiatric treatment if that was indicated, give him food and a place to live, and make sure he was getting along all right - everything that was necessary. At the last moment, one of the doctors we are suing squelched this by writing a letter to his underling saying that this CPA must himself be crazy to want to take custody of "X".

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Mr. Bruce Ennis is a practicing attorney who has participated in the Alabama Wyatt v. Stickney case and the Willowbrook suit in New York. He is one of the founders of the National Council on the Rights of the Mentally Impaired.

A Commentary on the Pennsylvania Right to Education Suit

Thomas Gilhool

Let me walk you through the Pennsylvania case - the general considerations that I think will bear upon your situation and your role in the months ahead.

Fifteen retarded children, suing on behalf of themselves and all other retarded children, along with the Pennsylvania Association for Retarded, went to federal court on January 7, 1971. They took with them as defendants the Commonwealth of Pennsylvania, the Secretary of Education, the State Board of Education, the Secretary of the Department of Public Welfare, and thirteen individual school districts in the Commonwealth of Pennsylvania.

They went to court for two things, for a "zero reject" system of education and for a procedure that would, among other things, guarantee a place for parents in the development of their child's educational program. By going to court on January 7, 1971, these retarded children placed themselves in a very old tradition of this country - the tradition of the use of the courts to achieve desired social ends. This tradition dates back at least to 1904 when W.E.B. DuBois and others were forming the National Association for the Advancement of Colored People. We are very familiar with the use of the courts by the civil rights movement in the late fifties and early sixties. More recently, women have begun to use the courts and, in 1971, mentally retarded citizens and their families adopted a similar strategy.

That tradition, which we are all now a part of, is a significant one. Let me note two things about it. First, it has a legal expression in a celebrated footnote by Chief Justice Stone in a Supreme Court decision in the early 1940's. Chief Justice Stone spoke about those citizens among us who are members of the discreet and silent minorities against whom there runs prejudice and who are therefore denied access to the ordinary processes of government. To those citizens, Chief Justice Stone suggested that the courts bear a special duty, a duty to scrutinize official acts of the state that may disadvantage such citizens. That tradition which we have joined is held together not only by a legal formulation but also by a certain set of social judgments and facts.

In the Pennsylvania case, for example, a basic social judgment was made of fourteen mentally retarded citizens and their families - that we are superior and they are inferior. Similar judgments have been made of each of the groups of which I am speaking - the retarded, the blacks, the poor and women. That judgment sets in motion a social process the end of which, I suppose, is best seen in institutionalization. It sets in motion another process as well. Those against whom the judgment is made have come themselves to

believe it and to internalize it. They feel fear, guilt, shame and very often act accordingly. The end result is timid action or no action at all.

Litigation has a great many uses, four of which I think you see in the Alabama and Pennsylvania cases: (1) the first is to achieve certain end objectives, in the Pennsylvania case a zero reject system of education; (2) the second is to create new forums, new places where citizens may assert their rights; (3) the third is to raise in court new facts and the need for more appropriate public responses and, thereby, sensitize the general citizenry, the legislature and other social institutions; and (4) to permit citizens through a petition for regress to express themselves and, perhaps to change their concept of themselves. I want to suggest to you that the Pennsylvania case and other similar suits are changing the notion of self that retarded citizens have and that their families have and, I think, will change the sense of self of professionals in the field of retardation as well.

Let me start with the argument for zero reject education. That was the primary reason why we filed our case in Pennsylvania. The case for education and training available to all retarded children rested upon two rather straight forward notions; the first was a legal concept, and the second was a factual one.

The legal approach rested upon the Supreme Court's decision in the landmark case of Brown v. The Board of Education. In that suit the United States Supreme Court said the following:

> *Education is required in the performance of our most basic responsibilities. It is the very foundation of good citizenship. It is a principal instrument for awakening the child to cultural values and preparing him for later training, and in helping him to adjust normally to his environment. It is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. The opportunity of an education, where the state has undertaken to provide it to any, is a right which must be made to all on equal terms.*

If it is doubtful that any ordinary child may reasonably be expected to succeed in life if he is denied an education, then it is trebly clear that the retarded child may not be expected to succeed in life. The ordinary child may learn "willy-nilly" while wandering in the woods, in the streets, riding buses, watching TV, or whatever; but the retarded child, if he or she is to learn, requires a formal structured program of education and training.

Second, unlike the ordinary child to whom the Supreme Court was referring in the Brown case, the retarded child is not merely destined to fail in life; without adequate education, the retarded child is also in jeopardy of losing his or her liberty.

Evidence in front of the court in the Pennsylvania case indicated that, without a proper program of education, the rate of institutionalization increases significantly. Evidence also indicated that without the self-help skills that education and training alone can bring, the death rate among retarded institutional residents is significantly higher than it ought to be. The retarded child, therefore, without education is at risk of loss of liberty and perhaps of life itself.

The factual basis of the case is equally simple and straightforward. There is no such thing as an uneducable or untrainable child. Every retarded person is capable of benefitting from an education. With a proper program of education and training, for every thirty retarded children, twenty-five are capable of obtaining social and financial self-sufficiency in the ordinary market place. Four of the thirty, with adequate education and training, are capable of social and financial self-sufficiency in a sheltered environment. The remaining one, with an education, is capable of achieving a significant degree of self-care. That is a fact. It was not always a fact. Twenty years ago one could not have made that assertion without significant fear of contradiction. The Supreme Court in the Brown case suggested that a statute based upon a specific set of facts may be constitutional at the time it is written, but when the facts change, it may become unconstitutional. The facts changed here in our perceptions of the educability of retarded children.

Ignacy Goldberg of Columbia University Teacher's College and Jim Gallager, the first director of the Bureau for Education of the Handicapped in HEW, took the stand and testified to the educability of all retarded children. That is the basis of the right to education concept. It is not unfamiliar. The case for zero reject education has been made increasingly across the country for at least the twenty-three years in which the parent movement has existed.

The circumstances in Pennsylvania on January 7, 1971 with respect to delivery of education to all retarded children was not at all unfamiliar. Pennsylvania was among the national leaders in providing education for the retarded. The leaders of special education in Pennsylvania have been committed for a long period of time to the goal of delivering education to all retarded children. Considerable effort has been expended on this effort. Even in Pennsylvania's constitution, at least in paragraphs of the laws, it speaks in terms of the constitutional right of all children to education. The school code says that it is the goal of the Commonwealth of Pennsylvania to provide a proper program of training and education to all retarded children in the state.

The facts, of course, were very different and so, in a significant degree, was the law. On the one hand, the law said ALL but a couple of chapters later it said, in effect, "Well, there are certain conditions under which children may be excluded from

school." Some statutes indicate retarded children may be excluded if they are uneducable or untrainable. They may be excused or exempted if they can no longer profit from an education. In addition, the Pennsylvania statutes said that a child's admission to education may be postponed until he has achieved a mental age of five. All of you know that a child whose I.Q. measures roughly 35 or below may never be able to achieve the mental age of five and thus qualify for an education.

In addition to those statutorily sanctioned passages that excluded thousands of retarded children from education in Pennsylvania, there was a widespread pattern of practice in most cases legitimated by statute or by regulation, under which retarded children were being denied an education: the practice of saying to children, "Don't come around until you are eight and go away when you are seventeen"; the practice of saying to children and their parents, "You are not for us"; the process of disciplinary exclusion; the practice of saying by way of a look, a glance, or a judgment, "Go away, we are not interested in you,"when the five or six year old child appears at the school. In general, that was the pattern of law in practice in Pennsylvania. However, it was not universal.

I cannot tell you even now, let alone as of January, 1971, how many children are being excluded from education in Pennsylvania. For despite the fact that the Pennsylvania school code requires every school district to maintain and to update annually a census of all handicapped children (including those out of school), Pennsylvania has not and never has had any such census. I would guess each of the school codes in your states have a similar provision and each of your Departments of Education cannot ascertain how many children are out of school.

Arguments in the Pennsylvania case were presented to the court between January, 1971 and August, 1971. We went to trial for the main hearing on August 12, 1971, and those gentlemen whom I have mentioned earlier testified. That evening the Deputy Attorney General said he would like to settle out of court.

The background may be of interest to you. As is the practice in the course of any free trial, we submitted to the Attorney General the list of people we intended to call as witnesses; he sat down with his people at the Department of Education and the Department of Public Welfare and asked who these people were. The officials described them to him. The Attorney General asked his people what the plaintiffs were going to say, and they told him. Then, the Attorney General wanted to know how the Commonwealth should respond. They said, "We can say nothing in response. They are the best people our field has to offer. They are the leaders of the profession. What they say is true and we would have to agree."

So, on the basis of the consent agreement, which was signed originally on October 7, 1971, the court issued a series of approxi-

mately a dozen injunctions requiring a program of education and training, appropriate to each child's capacity, for every retarded child in the Commonwealth. This was ordered to be carried out as soon as possible, but in no event later than September, 1972. A series of injunctions were issued that said: (1) no longer use those statutory exclusion provisions which I mentioned earlier; (2) no longer engage in the aforementioned exclusionary practices; (3) make available a means of instruction to the retarded, training for the severely limited and intensive educational experiences designed to prepare each child for better adjustment to his or her social environment; (4) establish a tuition reimbursement for payment of the educational costs for retarded children in private schools on the same basis as it is provided to children with other exceptionalities; and (5) provide a preschool education program for retarded children wherever a program of preschool education and training is being delivered for every child in the Commonwealth or in that particular locality. Upon request of both of the parties, the court appointed two masters to oversee the process of implementation of the injunctions. Those two masters were Dennis Haggarty, a Philadelphia lawyer, a consultant to the President's Committee on Mental Retardation and Co-chairman of the American Bar Association Subcommittee on Law and the Mentally Retarded, and Herb Goldstein, the Chairman of the Special Education Department at Yeshiva University.

The court directed the Commonwealth defendants to prepare and present to the masters two plans: (1) the first to identify, locate and evaluate all out-of-school children; and (2) the second to outline a system for delivering the education and training programs required by retarded children. A great deal has happened between October 7, 1971, and the present - matters which perhaps we can address in more detail in our conversation about the case. We spent a number of months in court in hearings and in arguments about the objections raised by the defendants' school districts which were unhappy with the judgment. The final opinion of the court came on May 5, 1972.

There was a second objective to the suit and that was the establishment of a due process hearing. You may remember the article in the September, 1971 issue of Exceptional Children. In the five county metropolitan area of Philadelphia, at least 25 percent (and perhaps as many as 68 percent) of the children assigned to retarded, educable classes were misassigned. Those children should have been in regular classes, and some should have been receiving other supportive services. The incidence in misclassification is very high. Jane Mercer has found a similar level of misclassification in Riverside, California. As you know, the literature indicates that similar rates of misclassification are common in all parts of the country. The argument for a due process hearing before a child's educational assignment may be changed rested upon that incidence of misclassification and upon the stigma associated with special class placement.

Wisconsin had a very interesting statute that said that if a sheriff and other local officials decided that a person had too often been publicly drunk, they could post the name of that person in the town square and outside of the entrance to each of the pubs in that town. Mrs. Smith, in the opinion of the sheriff, was publicly drunk too often and she objected and went to court. The court said, in upholding her position, the following: "The only issue here present is whether the label of characterization given a person, by posting in that case, though a mark of illness to some, is to others a stigma or badge of disgrace that procedural due process requires notice and the opportunity to be heard." We agree with the district court that the private interest is such that those requirements must be met. "Only," the court said, "when the whole proceedings leading to the pinning of an unsavory label upon a person are aired, can oppressive results be prevented." In the Pennsylvania case, at argument on the motion to convene, the judge suggested to the Commonwealth that they ought to come to terms on the due process claim.

On June 17, we came to terms on the due process claim. The agreement and the order of the court is that, before any child's education assignment can be changed from regular class to special class, among the varieties of special classes, from special class to home-bound instruction or tuition reimbursement, or vice-versa, the parent must be given notice of the change of assignment and a detailed statement, in writing, of the reasons for that recommendation. The parent also must be notified of his opportunity to be heard. This was agreed to by both parties of the litigation and the court also ordered that notice of the opportunity to be heard must be given to the parents of all retarded children periodically - automatically. In addition, every two years, in the course of their education and every year that the parents so request, a statement of reasons must be given. The parent is entitled to access to all of the child's school records. The parent is entitled to an independent evaluation of the child for use at the hearing. The parent must be told of the address and the telephone number of the local chapter of the Association of Retarded Children and the Association's availability to assist in pursuing that hearing. Parents also must be told of the availability of legal counsel, at no cost if the parent is unable to afford counsel. The required hearing must be held in front of the Secretary of Education for the Commonwealth or his designee.

The federal court isn't about to enter into judgments about the question of the quality of education provided for the child. The due process hearing, however, is a forum where questions of quality of program may, and have been, raised and resolved.

In brief, that explains "zero reject" and the new forum - the due process hearing. Let me not say anything further about the use of litigation for bringing matters to the attention of the public. Instead, let me direct your attention to the opportunity to express oneself and perhaps even change one's conception of oneself.

The preliminary order on October 7, directed the defendants to take immediate steps to place the thirteen individually named plaintiffs in the suit in a program of education and training suitable to their capacities. A few days after October 7, the school psychologist of one of the defendant school districts visited the home of one of the plaintiff children and he said to the mother, "I am going to do you a favor, I am going to put John back in school." And she said, "You are not going to do me a favor, you are going to give to John what he is entitled to."

In the same week, another school psychologist visited the home of the parents of one of the other children and stated in effect that school officials intended to obey the court injunction and place their son in a class. However, the class was the same one their son had been in before; it had not met his educational needs and, as a result, the boy began making disturbances and disrupting the class and was sent home. The psychologist indicated that the parents might anticipate the same sequence of events but that the child would be given a due process hearing. The parent said a great many things to the school psychologist when he asked the mother if she would want to put her son through all of that. In essence what she said was, "Sir, your language is wrong. It is no longer the case that the child has to fit the class. Rather, sir, the class must fit the child."

The language has changed. It is no longer the language of favor or benefit. It is no longer the fact that what comes to the retarded child and his family comes out of the good will and the graciousness of others. It is now the language of rights. What comes, comes as a right. It is really not the language of love and kindness but of justice.

Another example of change in self-conception is a school psychologist in Pennsylvania who two years ago, after having evaluated a child, defined and prescribed an educational program of "x, y and z" content and sent the recommendation to the school superintendent. He often got back the response: "That is really a good program and I wish we could provide it for this child, but we can't. So you file it; maybe in a couple of years we'll be able to provide that program for that child." The school psychologist had no recourse but to return to his desk and slam the door in anger and be sad. The school psychologist has other recourses now. A hearing procedure is available to that psychologist to exercise his professional responsibilities.

Clearly, in the Pennsylvania litigation, and in the course of every other litigation before and after, there has been presented by the litigation extraordinary opportunities for professionals who are good. It is the opportunity to use the leverage of a court suit and court judgment to achieve those things which, in their professional judgment, must be achieved.

I was reminded, when Dr. Hottel was talking, about how often professionals, on all sides of the world, have managed to finesse their professional responsibility. For example, there is the case which happened just across the river in Oakland. A social worker was ordered to go on a midnight search early on a Sunday morning to look under the beds of public assistance recipients and find out if men were hiding there. He said, "No, I will not go, because I regard that search as an invasion to my client's right to privacy under the 4th Amendment." He was fired. The state Civil Service Commission upheld his firing, but the California Supreme Court unanimously reversed that decision saying in effect: "Yes, indeed he can, and, by implication, should undertake to raise the rights of his clients." That is the sort of professional role that we are dealing with here today.

Let me close with just two other pieces of information that may be, in some sense, useful to you in leveraging the events of the last two years into accomplishments in terms of the rights of the retarded citizens. First, let me walk through the list of states in which the right to education issue is presently pending. Pennsylvania, of course, and Washington, D.C., both of which have come to judgment now. At least the court has ruled from the bench in the D.C. case that summary judgment is to be granted and the order is expected momentarily. This is a suit, by the way, which is framed not only in terms of retarded children, but in terms of the whole class of exceptional children with all the varying exceptionalities that may be involved - framing, which I trust, will be the prevalent one in all of the future cases. Louisiana is in court. Massachusetts is in court. Michigan and North Carolina are in five courts. Before this month is out, Illinois, Colorado, Nevada and North Dakota will be in court.

A census has been taken of legislative activities since the Pennsylvania case got to the stage of judgment. In that period of time there has been a significant increase of legislative activity. Some 900 bills have been introduced in the fifty state legislatures dealing with the rights of exceptional children to education. Of those 900, some 296 have been passed. The most noteworthy perhaps is the Tennessee act which Dave Ray spoke of earlier.

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Mr. Thomas Gilhool is an attorney who represented the plaintiffs in the landmark Pennsylvania right to education suit. Presently, Mr. Gilhool is a professor at the University of Southern California Law Center.

The Mentally Retarded and California Law

Sterling Ross

We are on the eve of an all-out struggle on behalf of the mentally retarded for dignity and legal equality, not only in California, but throughout the nation. The area that I would like to talk about is -- What are these basic rights that we keep talking about for the retarded? We have thus far been speaking in platitudes about basic rights.

Can a mentally retarded person in California be held criminally liable for actions or be convicted of a crime? What is the standard for defining the criminal responsibility of the mentally retarded person in this state?

There is a section of the Penal Code of California which deals with the mental competence of a person. Section 1368 says that no person shall stand trial unless he can understand the charges against him and participate in his own defense.

Under Section 1370, if a person is so "insane" that he cannot understand the charges against him or help in his own defense, he must be sent to a state hospital until he recovers his sanity so that he can stand trial. Twenty-six mentally retarded persons have been sent to state hospitals under this section to recover from their retardation so they can stand trial. This constitutes involuntary commitment for life for persons who were not even tried for the charge against them. Can you believe it? It was not until last year that we were able to pass legislation which provides a system to diagnose and evaluate the retarded person's competence to stand trail. This legislation acted retroactively to re-evaluate the condition of the twenty-six persons previously committed.

Why, in many parts of the law, are the mentally retarded still not viewed as human beings? Why have the retarded been denied basic rights? I think it is because retardation is the only form of handicap where the handicapped person cannot speak for himself. The blind are able to lobby in Sacramento. They walk up to the podium in committee hearings and testify on their own behalf. Only in this last year have a few lawyers become advocates for the retarded -- and only in this last year has initial progress occurred.

In this state, mentally ill residents in state hospitals are guaranteed certain rights: to wear their own clothes; to keep and to use their own personal possessions, including toilet articles; to keep and to be allowed to spend a reasonable sum of their own money for canteen expenses and small purchases; to have access to individual storage space for private use; to see visitors each day; to have reasonable access to telephones, both to make and receive confidential calls; to have ready access to letter writing materials, including stamps, and to mail and receive unopened correspondence; to refuse shock treatment; and to refuse a lobotomy.

The involuntarily committed mentally retarded patient in state hospitals has none of these rights. It was a legislative oversight that they did not make this section applicable to the involuntarily committed mentally retarded person. Still, in California, the greatest number of retarded patients have been judicially committed, though today most are admitted voluntarily through regional centers. Legislation is now pending in Sacramento to make these basic rights applicable to the involuntarily committed retarded patient.

California's state hospitals for the mentally retarded are rapidly being phased out. Pursuant to the concept of normalization, more patients than ever before are being discharged from hospitals and placed in the community. It is hoped that there they will have the opportunity to experience the rights, obligations and responsibilities that normal citizens encounter -- to be treated as a human being, to develop untapped potential, to grow in every way.

The move to the community, however, presents a whole new range of legal problems. Because the state operates no facilities for the retarded in the community, discharged patients are placed in private facilities, most often board and care homes serving six or fewer residents. These homes must be licensed to operate, but four different state agencies license these homes. Their overlapping jurisdiction and varying licensing requirements produce confusion and mismanagement.

Once a mentally retarded person is placed in the community, who is legally responsible for him? If he has been discharged from a state hospital, the hospital no longer has any legal responsibility for him. The operator of the home in which he has been placed is not legally responsible for him. If he is 18 years of age or over and, therefore, an adult, the natural parents are no longer legally responsible for their child unless they are appointed guardians. Consequently, many mentally retarded persons are in a twilight zone of legal responsibility. They have no advocate. The law holds no one legally responsible for their welfare.

Many counties and municipalities are enforcing restrictive zoning ordinances which prohibit board and care homes for the retarded from obtaining zoning clearance in residential zones. These homes are, therefore, limited to commercial or industrial zones or apartment areas. I have been traveling all over the state speaking for applicants before city and county zoning commissions trying to get permits to operate these homes. Litigation is now pending in San Francisco on zoning restrictions, and we have introduced legislation in Sacramento to attack this problem.

Peace officers are given no training in recognizing and handling the retarded. I receive calls periodically from people who report to me that a mentally retarded person has been picked up by the police as drunk and put in jail. The police in this state have no understanding about what mental retardation is. They must have, as part of their mandatory curriculum, a course on mental retardation.

Though I have been speaking a lot about laws and legal problems, it must be obvious that the real problem with which we all must deal, lawyers and non-lawyers, is public attitudes. Until popular misconceptions about the retarded can be dispelled, until homeowners can be convinced that the retarded are not criminally dangerous, until peace officers can be shown that the retarded are not drunk or mentally ill, until legislators can learn that the retarded are no longer "idiots" and "imbeciles", until all people begin to look beyond physical differences such as a withered limb or black face and search out what is inside people, not much progress will occur. As in 1954, we are on the eve of a vast legal effort to achieve a decent life for a group of human beings. If, as laws change, attitudes follow, our goal can be attained.

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Mr. Sterling L. Ross, Jr. is an attorney for the California Association for the Retarded.

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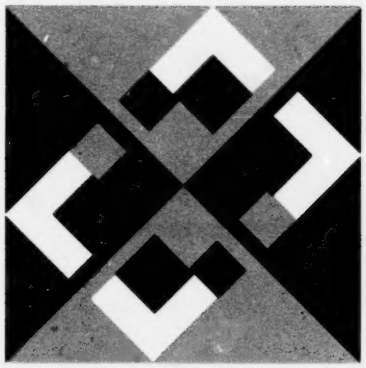

THE RIGHT TO TREATMENT:

A COMMENTARY ON LITIGATION IN ALABAMA

A Panel Discussion on Wyatt vs. Stickney Case

I. Background Information[1]

In September, 1970, shortly after Dr. Stonewall B. Stickney, Commissioner of Mental Health in Alabama, announced a reduction in force at Bryce State Hospital, a large state hospital for the mentally ill, the employees filed a suit (Wyatt v. Stickney) in Federal District Court against the state mental health officials and hospital administrators. The plaintiffs protested their severance without notice or hearing and claimed that their dismissal would detrimentally affect the quality of care at Bryce, thus denying the patients their constitutional right to treatment.

Judge Frank Johnson of the Federal District Court of Alabama ruled in March, 1971, that patients who were involuntarily committed to Bryce Hospital because of mental illness were being denied their constitutional right to individualized treatment. The defendants were given six months in which to bring treatment up to constitutional standards.

Because of the national implications of the suit, it was enlarged to a class action. During the summer of 1971, the suit was amended, and the class was expanded to include residents at Partlow State School and Hospital, a state institution for the mentally retarded, and Searcy State Hospital, the other public hospital for the mentally ill.

The court invited the United States to participate in the case as an amicus curiae and a six-member team of FBI agents was dispatched to Partlow to investigate the conditions and to interview the staff of the facility. Subsequently, several national organizations - the American Psychological Association, the American Orthopsychiatric Association, the American Civil Liberties Union and the American Association on Mental Deficiency - were invited to serve as amici curiae.

After reviewing the defendants' six-month progress report in December, 1971, Judge Johnson found that the state officials had failed to establish minimum standards for adequate treatment. The Court set a hearing to develop comprehensive and

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[1] Adapted from Friedman, Paul, Mental Retardation and the Law, A Report on Status of Current Court Cases (Washington, D.C.: Office of Mental Retardation Coordination, U.S. Department of Health, Education, and Welfare, April, 1972), pp. 1-4.

effective standards for minimum adequate treatment and habilitation of residents in state mental health facilities.

In late February, 1971, a three-day hearing was held on the mental retardation aspects of the case. As a result of the expert testimony about the deplorable conditions at Partlow, Judge Johnson issued an interim emergency order. This decree required the state to employ 300 additional ward personnel within thirty days, to make the buildings fire safe and to control the distribution of drugs.

On April 13, 1972, Judge Johnson issued a final ruling ordering state mental health officials to implement a detailed series of 49 minimum habilitation standards at Partlow. In addition, the Court appointed a seven-member human rights committee, gave the state sixty days in which to hire a professionally qualified and experienced administrator as superintendent of Partlow and required the state to prepare and to present to the Court within six months a report reflecting the progress of implementation of the court order.

Subsequently, the State of Alabama has appealed the case in the U.S. Court of Appeals for the Fifth Circuit. Oral arguments were heard on December 6, 1972. However, the Court has not yet issued its opinion.

II. Purpose of Panel

This panel, consisting of three individuals intimately involved in the Wyatt v. Stickney case, was developed to provide the conference participants with additional background information and insight into the development of the case. As such, the discussion was of an informal nature and, rather than focusing on any specific aspects of the Partlow case, tended to involve many diverse facets ranging from chronological development of the case itself to the issues of professionalism and the concept of normalization.

III. Panel Members

Mr. George Dean was attorney for the plaintiffs in this suit.

Mr. Jerry Wood was Deputy Attorney General for the Alabama Mental Health Board and represented the defendants.

Dr. John Hottel was the Deputy Commissioner for Mental Health for the State of Alabama and, at the time of this conference, the interim superintendent of Partlow State School and Hospital.

IV. Panel Discussion

Mr. Dean: Back in the Fall of 1970, I was in Tuscaloosa, Alabama. Between 90 and 117 employees of Bryce Hospital in Tuscaloosa, a large mental institution in Alabama, had received notices that their employment would be terminated. A great many of these people were professional psychologists. The department of social work in particular, and the department of psychology were really decimated by these terminations. The excuse was given that the Alabama Mental Health Board had seen a decrease in taxes from anticipated cigarette revenue. It later turned out that there really was not a decrease, there was an increase in taxes; but that really does not have anything to do with the case. It just points out the first of a series of hundreds of blunders on the part of the Mental Health Board.

These people came to me as a group and asked me whether I would represent them. Other lawyers whom they had talked to would not represent them and told them they did not have a case because professionals could be fired.

I somehow immediately conceptualized when these people came to me at a friend's home, that there had to be a constitutional right to treatment and that you could not treat without professionals. I also conceptualized that patients had to be part of the lawsuit to enforce the complete right. After almost two years now, the case has grown and expanded in every direction to include retardation.

Mr. Wood: The Alabama Mental Health Board is a 13-member public corporation. The members are appointed for six-year terms, but are not necessarily responsive to the Administration. Our commissioner is not a cabinet man but is responsible to the Board. Although I am the Assistant Attorney General, I am not responsible to the attorney general; I am responsible to the Board and paid by the Board.

I do remember those first days when this looked like a matter primarily involving the employees. Our first answer to the complaint treated that problem more actively than the right to treatment aspect of the case. Of course, very soon we recognized that the Court was more interested in violations within the right to treatment and not the least bit interested in those employees that had been laid off.

This case came up in October, 1970 with the primary thrust being right to treatment. We had a hearing in January, 1971, and Judge Johnson issued his first order in March, 1971 and gave the defendants a pretty realistic job. We had a complicated set of facts. When these people were laid off, Dr.

Stickney, the Commissioner, suggested publicly that we were going to the unit system or a departmental system. The Court asked us though, in March, to report back to the Court within 90 days the primary mission and goals of Bryce State Hospital. It was limited at that time to Bryce Hospital, an institution for the mentally ill. We received a rather drastic order on December 10, 1971, which said the defendants had had an opportunity to respond to the Court by setting out some constitutionally accepted minimal standards but had failed, so the Court would now do it judicially. In January and February, 1972, we had extensive hearings. Meanwhile, Partlow and another institution for the mentally ill were added to the case.

Perhaps we should stop here and respond to specific questions, but I feel I should say one thing first. I say this to all the lawyers that are here; it is a very basic, elementary thing. Don't rely on your administrators or any third person or even second person to tell you what the conditions are. You go and see and be sure that you have a complete understanding of what conditions really prevail. Look at the records, know what is going on in your habilitation and treatment programs because even your key officials are functioning a hundred miles away, as I was doing. We thought we knew some things that we did not really know.

Dr. Hottel: I really became involved in this case only after the judge issued his emergency order in March, 1972. Prior to that time, I was Deputy Commissioner for Administration and was involved with administrative organization and program planning and budgeting. When the emergency order was issued in March, 1972, Commissioner Stickney formed a task force to go to Partlow and implement this court order. On that day he appointed me interim superintendent. I have done nothing else since.

Mr. Wood: It was obvious to the defendants from any number of standpoints, that a classical defense posture was just not the right approach. It really would not do just to stand up and say, "This is the way we are doing it, but we are going to defend it." We looked carefully at Judge Bazelon's decisions; we looked at the Georgetown symposium; we looked at our own laws; and we looked at what we were doing and, without quoting the source, one of the key defendants said that there is no way for us to win this case except at the expense of the patients. So when you represent the state and you represent this set of defendants who are members of a public corporation called the MH Board, you almost enter into a juggling act being sure that you are doing what is legal and ethical and proper for all your clients.

Mr. Dean: You are in for a lot of trouble, all of you. You can bet on that. These lawsuits are not fun. Dave Ray says

that the administrators welcome them and that they should not feel that these lawsuits are a threat but that they should be a challenge to your ability. I have not known any of them to be fun for the other side yet.

Mr. Wood: From 1965 until the current operating budget, Alabama's per diem has gone from about $3.50 a day to $10.50 plus a day. About 30 million plus state dollars have gone into building new facilities. We are utilizing the regional concept. We have an 8 million dollar facility in Decatur, and three others planned around the state and all of our people at the state level are saying, "My God, look what we have done for mental health and mental retardation in the last few years. If these people will just leave us alone, look where we will go." Of course, you have a plaintiff coming in and saying, "We have been waiting a long time and we are not going to wait until you get up to par."

Mr. Dean: Injunctions are orders from the courts to do things. I do not know of any way to take care of people's feelings, and I am sorry about people who get in the way of constitutional rights.

Dr. Ornstein: With administrators who want to do good things, who recognize the problems that exist, how in Alabama or in any other state, can you promote the legislature to get things done?

Mr. Dean: It is not necessarily just promoting the legislature. You will find as superintendent, that when you buck your request for four new psychologists, the state personnel man may say, "Oh, we can't do this!" You have to understand that he is under an injunction, too, as an employee of the Board. So, I may have to get the personnel man before Judge Johnson.

Or you say, "Well, what are we going to do about this aide who has kicked this man?" Dr. Hottel had a case the other day, and he took rather drastic measures. He just shook the whole place down; transferred everybody across the river and fired one man. Now, he has got a personnel board hearing and he thinks they may lose that hearing. He might lose it. But if they had turned the aide over to me and had let me cite him for contempt of court and taken him before Judge Johnson without a jury, the employee would have himself some real problems for that simple little contempt. The superintendents and the mental health people can rely on the lawyers to help them in any of these areas, such as union related matters.

The Mental Health Board all throughout this case said that it could not find people to work at the salary offered. The day after Judge Johnson ordered the hiring of 300 people within 30

days, the Tuscaloosa paper carried a story on the court order and over 1,000 people showed up at the front door of Partlow. You will find people who will work, but you must cut through some of the bureaucracy, and many of you are a part of the bureaucracy itself.

I see Mike Thrasher of the Justice Department in the back of the room. It is a strange thing for me to praise anything in the Republican Administration, but I am going to tell you that because of this case and others the U.S. Justice Department, Civil Rights Division, has set up an Office of Institutions and Public Facilities to do nothing but handle this type of case in all institutions, prisons, juvenile homes, schools for retarded, and mental hospitals. Ira Dement, a United States attorney in Montgomery, who presented this case, and I recommended this to the Justice Department. There are now 12 people on the staff, and they do a good job and provide an invaluable service.

I am interested in how Dr. Hottel began his attempt to carry out the court order. Can you tell us a little more about how you got money? How you mobilized things?

Dr. Hottel: I did not get any money. I just started spending money that was authorized over the year faster than it was authorized to be spent. We have spent no new dollars at this point. However, I did not do this alone. The Commissioner organized a task force, and the emergency order, if you are familiar with it, had nine or ten stipulations. He divided these among the task force members. My major responsibility was that 300 employees had to be hired in thirty days. That could have been a catastrophe if it had been handled just within the letter of the law. In order to make those 300 employees viable, I had to employ 450, not 300. What I did was to relieve all of the trained aides who were doing other kinds of functions from those other functions so that they could begin to supervise these 300 new workers on the job. I did a lot of things quickly. After hiring the new employees, I scattered them over 14 large buildings, each with four to six wards in them, so that Partlow would not have a large number of new employees in any one place. There would be one or two scattered over three shifts with adequate supervision. Then I began to look just at the administrative management of Partlow. It had been operated for three years by a physician who had not shown a great deal of skill in administrative organization and for three months by a very competent young man right out of graduate school who had no administrative experience. Therefore, I began to make administrative changes and assign administrative lines of responsibility so that I could find out who was accountable for what function. We have not resolved all of the problems at Partlow yet. It has been difficult. As Mr. Dean has indicated, it has been very difficult to break some of the historical traditions that operate within state government. I

think we are well on the way to doing it, but it takes a lot of time. Even though you see what ought to be done, it is sometimes very difficult to get it done.

Some hospital administrators go so far as to seek out people who may be dissident and who might strike to get support for their hospital. You would think the hospital would, in a sense, embrace this because it is really what many of these hospital administrators have been seeking.

Dr. Hottel: I think Mr. Dean and I share a common fear. To move out rapidly and to implement the judge's order by the letter may be in the long run harmful to the mentally retarded in the State of Alabama because we have an overcrowded institution, an institution that should rightfully have about 600 residents in it, but which instead has 1,950 residents. If we geared up to serve 1,950 residents in that institution, we could wind up with another self-perpetuating, large, well-staffed institution.

Mr. Dean: This would be a most tragic thing. It would make me ashamed to have ever heard about this lawsuit. My entire purpose in this lawsuit was to make handling the retarded in institutions like Partlow so costly that no state in the Union could afford it.

Would you please respond to the peonage issue?

Dr. Hottel: Peonage is easily resolved, or at least I found it easily resolved. The superintendent is still something of a god, and all you have to do is issue a statement that you will not work any more residents. On the other hand, even with the threat of the court hanging over you, you will have staff members who are convinced that they are right and that the work is good for the residents.

Mr. Dean: Some superintendents would welcome the court case almost as a friendly suit. Our whole system of law is an adversary system; this side fights and that side fights, and then truth rises from the ashes. Egos get in the way, no matter how friendly you are when you start. One of the greatest crimes ever committed has been done in the name of professionals. The state was going to use aides to deliver mental health care. They did not need professionals. Dr. Stickney and Dr. Folsom both took the stand and testified that staffing ratios of one Ph.D. psychologist to 1,500 people, no board certified psychiatrist, and, I believe, three social workers, would be adequate to deliver minimum constitutional requirements in mental health.

Dr. Ornstein: Is the next step then to require whoever controls the foster home placement program, the intermediate care facility program, the nursing home program and the health office to provide services to the mentally retarded in a community setting?

Mr. Dean: The full range of models of the normalization process are the only alternatives for many reasons. For example, they are

the least restrictive on a person's liberty. In Alabama, this big mental health institution had over 5,200 patients when this lawsuit was filed; it is now down to 3,600. Partlow is down from 2,200 residents to 1,900, and the institution may not take any more residents as a result of the court order. Now, this puts the pressure on all of you who are worried about the legislature. In Alabama, there is no need, in my opinion, for that much funding. Let me give you some examples: A year ago, Partlow's total budget was about 8 million dollars. After we put Linda Glenn, from the Nebraska ENCOR project, on the stand, she testified to the use of social service funds. For the first time in Alabama's history, state officials made an application for funding under Titles IVA and XVI of the Social Security Act. Dr. Hottel has approved, at my last information, $24.8 million for Partlow and there is another $46 million in the mill.

Dr. Hottel: Just one correction, Mr. Dean. It's not just for Partlow; it is for a statewide network of services of which Partlow is just to be one part.

Mr. Dean: That is correct and I say it only in those terms because until this lawsuit was filed there was no network. There was only Partlow.

Dr. Ornstein: When the state receives IVA, IVB, XI and XVI payments, these funds should not go to the general fund, but to the people for whom the match is intended.

Dr. Hottel: Under the federal regulations for the use of Social Security Amendment funds, the funds do not go into the general fund. They are reimbursed on the basis of service to an eligible client.

Dr. Ornstein: I can only tell you how social security funds are managed in Washington State. I surmise that some states are not applying for this money for programs for the mentally retarded. Washington is receiving social services funds for community programs and these dollars are going to the improvement of community programs for the mentally retarded. However, in the case of money received under Title XIX for institutional care, by and large the funds are reverted to the general fund in one way or another.

Mr. Wood: Perhaps we in Alabama are fortunate in at least one facet; our board has control over its own funds. These dollars do not go into the general fund.

Mr. Dean: All I am saying is that if you have seen one of these old institutions you have seen them all. Bruce Ennis and I were talking about the comparisons of Willowbrook and Partlow. He said he put many things in his complaint that he really did not know existed, but just on the basis of what he had seen at Partlow he knew they had to exist. Lo and behold, everything turned out

to be true. I think this would happen at your institutions to some degree. Things go on that you do not and cannot know about.

I think one of the things that bothers some of us as professionals is that at this time it is spooky to have parents of retarded, people associated with the ARC's and others asking what we think about institutions. I still do not have enough courage to tell them because, as part of the bureaucracy, we will be sacrificed.

Dr. Hottel: I think this is a personal professional problem that you have to resolve right from the outset. You have already been sacrificed. As a professional, you are gone so you might as well get in there and do what you think is right. None of us are going to survive in this profession in our present condition.

Mr. Horowitz: What sort of support, if any, did you have from the ARC?

Mr. Dean: It took a little while for them to get around to supporting us, but they came in at the tail end. All the groups were very supportive.

What if we talk about community resources rather than institutional resources?

Dr. Ornstein: In the State of Washington in particular, all institutional costs are free. Yet, if you have a child in a foster home and your income is over $3,600, you have to pay. What do you think a parent's decision is going to be? You pay for a foster home or you go to an institution for free. And the decision is often, "Gee, that's lovely - and it's free!"

Mr. Dean: We talked about Nebraska being a great place. The governor there appointed as director of institutions a man who had been superintendent of a nursing home. This new director walked around the streets one day, saw a microcephalic getting on the bus to go to work and said, "My God, this man needs a hospital." Now they want to build new hospitals, take people out of the community and put them back into Beatrice State Hospital. We are going to bring a lawsuit to establish the constitutional right to the least restrictive alternative to normalization. Once we do that, we become committed to a program of the least restrictive alternative on a person's liberty. As professionals, we should draw this line. Once you establish these viable alternatives and you have places to go, then as professionals you do not ever admit to yourselves that this person is hopeless. There must be some Hippocratic oath that the institution is not just the last resort, but that it is almost the unthinkable resort. Anytime you begin to restrict people's liberty in the name of doing good for them, then you are in danger. You begin to brand people when you say, "He cannot be helped."

Dr. Hottel: In just the last three months, I have given considerable thought to my behavior as a professional over the last twenty-five years and I have reached what to me has been an inescapable conclusion. I found that I have not been functioning as a professional, rather I have acquiesced to the pressures of the social system and become a representative of the power structure. I have let others make my professional decisions for me. This is why I said to you a while ago that we must sacrifice our professional selves if we are going to be professionals. We must do what we professionally think is right regardless of parents, the power structure or even George Dean. We have to exercise our professional judgments without the pressures of the threat of the penitentiary, of being fired, or of public censure.

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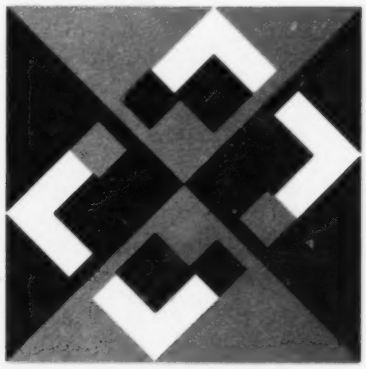

SAFEGUARDING THE RIGHTS OF THE MENTALLY HANDICAPPED: A LOOK TO THE FUTURE

A Discussion of Current and Future Trends in the Protection of Legal Rights of the Mentally Handicapped

I. *Workshop/Discussion Groups*

Utilizing the first day's speeches and panel discussion as a lead-in for the second day of the conference, participants were broken down into two discussion groups, each comprised of both legal and program oriented individuals. The primary purpose of the discussion groups was to consider eight major topic areas which had been brought out in the recent litigation. The topics for discussion were:

1. *Least Restrictive Habilitation Settings*
2. *Admittance Standards and Evaluation*
3. *Resident Labor*
4. *Right to Education*
5. *Voluntary and Involuntary Commitment*
6. *Payment for Care - Equity of Payment and Right to Services*
7. *Right to Humane Physical and Psychological Environments*
8. *Post-Institutionalization Plan and Placement*

Through the assignment of consultant speakers to lead the various groups, discussion focused on existing state programs, policies, and laws in direct relation to these various issues brought out by the law suits. These topics were discussed and evaluated in terms of existing state compliance and also in terms of possible solutions and future implementation.

Proceedings from the workshop groups have not been included, in part due to the informality of the discussions and also in consideration of their length. In summarizing the general tone of the workshop sessions, however, several consistent themes stood out, some of which were stated in the introduction. Along with the apparent lack of coordination between state program officials and attorneys general, the state representatives presented as their main areas of concern: (1) How can one accomplish the upgrading of programs and the meeting of those standards which the lawsuits have recommended; and (2) In direct relation to the first concern, how can the states acquire the appropriations and funding necessary to implement some of these changes. Prior to a lawsuit, it was felt by many that states would have difficulty in responding to these standards. However, during the discussions, by utilizing other states and the current lawsuits as resources, it was generally felt that new avenues for change could be attempted.

Some of the possible means to achieve those ends were also discussed in the following panel discussion on the "Problems of Implementation and the Future of the Mentally Handicapped."

While all of the topic areas were of importance and concern to the conference participants, it was felt that the issue of involuntary servitude of institutional residents was an area of both universal concern and one in which a model position could be taken. As a result, the position paper which appears in Appendix C was formulated to provide guidelines which could be used by the various state representatives in the hope that specific policies on the issue could be developed.

II. *Purpose of Panel*

This panel discussion marked the conclusion of the conference and was comprised of individuals representing a variety of perspectives - legal, program, and federal. Its task was basically to answer the question, "Where do we go from here?" It was hoped that the panel would serve as a focal point for the two previous days' work and would discuss what positive steps could now be taken in the provision of adequate services to ensure the rights of the mentally handicapped.

III. *Panel Members*

Mr. David Rosen is Superintendent of Macomb-Oakland Residential Center, Sterling Heights, Michigan. At the time of this conference he was the President of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded and also the President-elect of the American Association on Mental Deficiency.

Mr. Bruce Ennis is a practicing attorney who was one of the lawyers representing the plaintiffs in the Wyatt v. Stickney suit in Alabama and the Willowbrook case in New York. He is also one of the founders of the National Council on the Rights of the Mentally Impaired.

Mr. Paul Friedman is an attorney who represented the plaintiffs in the Wyatt v. Stickney case, a fellow of the Center for Law and Social Policy and managing attorney of the Mental Health Law Project based in Washington, D.C.

Dr. Stonewall B. Stickney at the time of this conference was the Commissioner of Mental Health for the Alabama Department of Mental Health. Presently, he is in private practice in Alabama and is also a consulting psychiatrist to the Montgomery Area Mental Health Authority.

Mr. Isaac Johnson is a Rehabilitation Services Administration official in the HEW Region X Office in Seattle, Washington.

IV. Panel Discussion

Mr. Horowitz: Can you tell us a little about the problems of implementation of the court order in the Alabama case?

Dr. Stickney: The first problem is, if the new court standards turn out to be as expensive as they are in Alabama, namely approximately double our per diem expenditure in three institutions, the question arises as to where to get the money right away. Our strategy was very simple: We informed our Board of Trustees, the Governor and his advisors in advance that this was coming. We also told them that once we agreed to standards of full accreditation and stipulated to a lot of detailed points that grow out of these standards, the cost was going to go up. We gave them cost figures similar to those used in Kentucky.

In other words, we are not going to shoot for a "blue sky standard" because accreditation in Massachusetts is not the same thing as accreditation in North Carolina or Kentucky. Rather, we are shooting for full accreditation with an expenditure that would be roughly appropriate to the area. Again, that just about doubles our expenditures. We were anticipating at that point that after the court order we would take the bill back to the Board and back to the Governor and say, "Now, this is what it will cost." I think we naively expected that the Governor and the Legislature would call a special session and raise the additional money to meet this new expense. The actual reception we got from the Governor and his advisors was that the financial burden was going to be intolerable, that there would be no special session at all, and that the case would be appealed.

It was later appealed by the Governor; it was appealed by the attorney general; but it was not appealed by the Mental Health Board. The Mental Health Board discussed this for nearly two months and resolved not to appeal the case because it would not be in the best interest of the residents and the patients in the institutions.

I do not know what happens in other states. Other states may not have other resources in their mental health and mental retardation department; but in Alabama, in a period of over one hundred years, the Mental Health Board has accumulated certain properties. There has been considerable pressure from various quarters throughout the state for the Board to divest itself of all of this property and apply the proceeds to the cost of meeting the new court imposed standards.

Keep in mind that there are two sets of standards which we are talking about. The physical plant standards, which relate to the humane environment, and the staffing standards. We estimated about 65 million dollars for the changes required in the physical plant and an additional 30 million dollars a year for the new staffing standards.

Mr. Horowitz: I am sure you must have thought of some alternative for the use of that $65 million - like community placement, community facilities. Would you address that at some point?

Dr. Stickney: As a result of letters imploring the Board to sell this property and use the proceeds to meet this new expense, the Board has decided to have its land holdings independently appraised. Estimates have varied as to the cash value of the land. The highest estimate I have heard is that all of the land put together might bring in 11 or 12 million dollars. Of course, the Board's position in the past has been, I think, justifiable in that they have held that it was unsound business practice to sell capital holdings and use the money for operating expenses to handle temporary crises. You then have no cushion against adversity. By adversity, I mean last year's experience in which we did not even have an appropriation.

I expect that they will come around and sell some property. It is not going to be nearly enough. Taking the capital improvement issue first, the next problem will be to get the Legislature to raise the capital improvement funds for the renovation of existing state facilities.

Now, the court order does not come right out and say it, but it gives a very broad hint that unless substantial progress has been made in funding by mid-October, the court will appoint a panel of masters to insure that proper funding does take place.

Another broad hint is that judicial funding might take place; namely, other agencies might be brought into the suit and enjoined against spending state funds for their agencies until the needs of our agency are met. Of course, some people are saying it cannot happen - that this would be an invasion of the executive and legislative authority by the judiciary. We do not know if this can happen or not. But unless substantial money is raised for capital improvements and renovation by our Board before mid-October, or by a special session of the Legislature there probably will be a master appointed and at least a new trial and judicial funding.

The situation is not so dire with regard to operating funds. This is because one of the hefty bi-products of the suit over the past year and a half has been to accelerate the development

of grants management people so that within a relatively short time Dr. Hottel and his staff have been able to generate proposals (mostly SRS and Titles I, IV, X, and XIV,) to the tune of about 86 million dollars. This is just in mental retardation alone. I think the total in mental health is 147 million dollars.

Most of these proposals will turn into contracts and if these contracts are signed, we will have a 220 million dollar program in mental retardation and mental illness. All we have to do is find the matching money. Right now, we could use currently budgeted funds for matching money. I think after June 30th it has to be new money, but I believe that Mr. Wood has held that we may be able to use next year's budget as new money. In regard to operating funds, we can now say to our Board and to the Legislature, "Gentlemen, here are the contracts and here are a couple hundred million dollars worth of federal funds. We have done our share. All you have to do is raise the matching money."

Probably, the crunch we will encounter in persuading the court of substantial progress in funding will not be in the area of operating funds, but will be in the area of capital improvements. Suppose we did have the necessary money. I am sure it has been brought out several times in the last couple of days that next to the constitutional right to adequate treatment, the strongest theme in these hearings was the necessity to employ the least restrictive environment for whatever treatment or habilitation program you had in mind for an individual.

This, of course, gives us additional backing for something we have been planning to do for three years which is to decentralize all of our operations - the big institutions. We would like to dismember them, relocate what is left of them around the state. This boils down specifically to some ideas having to do with new money for renovation.

The problem that we face, and I have heard other people from other states describe it, is the "millstone effect." You come in and want to do community psychiatry, and find that over 95% of your mental health and mental retardation budget is already devoted to three institutions. In addition, those institutions are so obsolete in every respect that you cannot take any money away from the institutional budget and move it into a community budget. Everybody knew that the investment should be very large in prevention, early intervention, children's programs, out-patient programs, etc., but there was not any money to do it. The reason we call this the "millstone effect" is that up until now we have said that until we raze these three institutions, we cannot really do much about a community services budget. One of the happy bi-products of this

court order (when you keep in mind the least restrictive alternatives) is that we can transform the monster institutional budget into a community budget by decentralization so that the institutional and community budgets become almost indistinguishable.

I am not talking about creating a lot of mini-institutions I am talking about such things as minor expansion of the inpatient component of the community mental health center; expansion of the day care component of the mental health center or community mental retardation program; and expansion of group home components (we refer to them as transitional living arrangements) which could include anything from foster homes, group homes, supervised apartments, unsupervised apartments, hotels, motels, and nursing homes as a last resort just before the state hospitals. We are talking about developing a whole spectrum of community living arrangements with community services to replace what we are now doing badly in institutions. In order to do this, we will have to use both the building budget and the operating budget formerly devoted to institutions and disburse funds throughout the state.

Mr. Horowitz: Mr. Ennis, what do you think a court order could do with respect to a budget so that we can accomplish the very laudable things that Dr. Stickney has talked about?

Mr. Ennis: If my impressions are correct, the regional center now being built in Mobile is going up at a cost of about $38,000 per bed for that 300 bed facility. New York is now building seven new state schools. The cost there is going to be 40 to 60 thousand dollars per bed. The cost of acquiring and building hostels and group homes is only about $10,000 per bed. I think the first thing a court order could do would be to identify how many people could live in a hostel or group home. Next, instead of building a nicer state school at 40 or 60 thousand dollars per bed, the court could order the state to spend less money and develop hostels or group homes. They could do that by enjoining the state from spending any money to build beds in the new state schools until the number of group homes needed has been acquired.

Mr. Rosen: There is another phenomenon occurring across the country, and that is the contracting of services. As an example, both New York and Pennsylvania have entered into contracts with independent builders to develop group homes. We are about to do the same thing in Michigan.

The cost to construct group homes by private enterprise as compared to state construction can be as much as a third less. The cost of operation is also less in some states, especially where the state is unionized or has a strong civil service

system. In fact, in talking with these private entrepreneurs, they are willing to contract with our state to take over our institutions. They also indicate that they will operate them for a third less. This is a whole new area of residential care which can be dangerous, but it deserves exploration.

In the State of Washington there are group homes which are operated by both non-profit and profit-making organizations, and there is not necessarily any distinction between the quality of one or the other. I believe there must be guidelines for the group homes. The department has to be involved and be assured, as we do in the state operated institutions, that these alternate living arrangements will function properly.

The cost of care in the institutions in Michigan averages well over $20 a day. The private group home operator is willing to build a facility in Michigan and charge $12.00 a day per bed for a group of residents not larger than 16. For a total of less than the $20 a day, they are also willing to provide, in addition to the group homes, activity buildings, workshops, day care services etc., in the community. In this case, the state does not provide the capital construction money or maintenance funds.

Mr. Ennis: We were asked about Medicaid money in the Willowbrook case. Willowbrook, for example, received between 32 and 45 million dollars in Medicaid reimbursements last year for residents in the intermediate care units. Half of the funds came from the federal government and half from the state social service department. The entire operating budget for Willowbrook was about 23 million dollars for the same number of residents. So Willowbrook got a lot more Medicaid money than the total budget. But it did not receive that money. The money went into the state treasury and was then parcelled out. A large chunk went to build psychiatric facilities for the mentally ill who had not generated that Medicaid money. Only a small part of it went for new state schools for the retarded and the balance of it, I am told, went to build new state highways and new administrative offices.

What we are asking the court to do is to enjoin the state from disbursing any of the Medicaid monies generated by Willowbrook residents for any purposes other than those that will directly benefit residents, either in operational services at Willowbrook or in building community facilities to which they can be transferred.

Dr. Ornstein: Social service money matches three to one and some states are not taking advantage of it. If a state is not utilizing this method, it might be well to explore this area because there is a lot of money involved. The social service titles may permit some activities in the institutions to enter into this reimbursable program.

Mr. Johnson: There is a significant factor here. All of these funds are reimbursable funds. In other words, the state spends four dollars out of which they get back three. Whether they use that three dollars they get back to improve services or to reimburse the state treasury, for whatever purpose they choose, is a question I am not prepared to answer. I do not know whether they are ever going to settle it.

Mr. Rosen: This, unfortunately, is the problem with many federally funded programs. This is a great concern of superintendents who are attempting to meet the regulations in order to get federal funds. The income expected is not used to upgrade the program within that particular facility but goes right back into the state treasury instead.

Dr. Stickney: You see that cannot happen in Alabama because of the way in which the department was created in 1965 by Act 881. If this department generates money by this means or any other means, this money goes to the Department of Mental Health.

Mr. Horowitz: In Washington State, where we have an umbrella agency with welfare, institutions, etc., all together, our budget people took the position, even on the purchase of service and the matching under IVA of the Social Security Titles, that state money can be replaced. This is the argument that we have been having and in my own view state effort must be maintained.

Mr. Johnson: In the case of Willowbrook, I do not see how any institution can generate more money than it spends, even under Title XIX.

Mr. Ennis: There are directives from the New York Department of Mental Hygiene and the Willowbrook administration to the physicians on the staff and the stenographers in the steno pool, stating, in essence, that all persons in certain buildings are to be listed as types of people who qualify for ICF services and if their IQ is too high to qualify, i.e., above 70, then the staff should estimate the lower IQ, never estimate a higher IQ. The stenographers fill out the Medicaid forms before these persons are even seen by a physician. They say what kind of person he is, how he is permanently disabled, and everything else that is required to qualify for Medicaid reimbursement. Then the physician signs the form. Two physicians on the staff refused to do that and were threatened with dismissal.

This brings us to the next point. If other states are like New York, there is an enormous inequality of amounts of money spent for the mentally retarded compared with the amounts spent for the mentally ill. At Willowbrook the annual rate per resident is seven thousand dollars. The annual rate per mentally ill child in New York State is fourteen thousand

dollars. The plaintiffs in the Willowbrook lawsuit could enjoin the state to spend the same amount of money on all persons receiving services, unless there is shown to be a justifiable reason for the difference. We are asking them to do that.

Another thing the court could do is to order the state, instead of paying the full per diem cost for institutional care, to take that money and go out into the community and purchase services. For example, in New York State there are a lot of private schools for the retarded. Dozens of them have very good programs, but the cost of these schools is about $5,000 per child per year. The state will pay up to $3,000 per year. The state will not pay more than the $3,000 toward private care, but it will pay $7,000 per year for a child in an institution. So, if the court ordered it, the state could take that same $7,000 and the same Willowbrook child and put him in a private residential school that has a decent on-going program.

In a lot of states (including New York) the laws permit involuntary hospitalization of the non-dangerous mentally ill and an enormous amount of program budget goes for that. We were thinking of asking the court to enjoin the State Department of Mental Hygiene from accepting any non-dangerous mentally ill persons for hospitals and spending that money on what we consider to be the more essential services of treating only the dangerous mentally ill or the mentally retarded. That would bring a lot of money.

The final, most drastic step which we considered taking in the Alabama case was to enjoin the state from spending any money on non-essential services.

Mr. Horowitz: I would like Paul Friedman to talk about what he sees in the future in this area.

Mr. Friedman: Let me briefly lay out what the next set of lawsuits will be, and where I think the movement will be. One item I think will be the whole commitment area. In the Jackson case, the United States Supreme Court, in its decision last week, noted and virtually called, I think, for more litigation in the area of commitment - commitment process, commitment standards, commitment rights. It noted that the involuntary commitment process affects vast numbers of people.

Another area is the civil process. It has rarely been scrutinized yet the most viable issues of human liberty and human civil rights and dignity are involved. This is the first Supreme Court case concerning that area. I think we will be seeing a sort of systematic exploration of the commitment process and what is the individual's rights, what is society's rights,

how is the balance struck, and what should the procedures be, etc.

Hand in hand with that, but on the mental illness side, I think will be something that we have briefed and discussed in the Wyatt case, but which the state would not stipulate to, and which the court declined to reach. I am referring to the concept of a durational amendment on involuntary civil commitment. I am not sure that the people we worked with, Dr. Stickney or Jerry Wood in the State of Alabama, were really opposed to this notion. I think they felt that this was something that should be passed by the legislature rather than be ordered by the court. However, if the legislature refuses to act, as in so many of these related areas, I think the court may ultimately have to reach the decision itself, and make an order.

Some members of our group believe that there should not be any involuntary civil commitments. Some of our other experts think that there may be some very limited role for involuntary commitment, such as in the case of a person who is ill and needs help but who, because of his own delusional system, does not recognize that he does need help and cannot be persuaded to voluntarily commit himself. All of our experts agree that this could be a proper occasion for involuntary commitment, perhaps involving only a week or ten days of hospitalization at the most. Then, if the patient, within that period of time, could not be persuaded that he needed treatment, the state, barring some overt and social act that would make a person susceptable to commitment through a criminal process, would have no right to restrict his liberty and keep him confined.

In the Wyatt brief, we argued that there were two very sound reasons for having a durational amendment. We did not specify whether this should be three months, six months, or maybe a year of involuntary commitment. We considered that as a compromise position, not our utopian or model position. The first theory was that there is a growing body of evidence that by simply staying in any institution you become institutionalized. Even if it is a progressive institution, it is still not the real world and it is not the community. Then the problems that institutionalization create for the patient are often more serious and substantial and more difficult to treat than the particular illness which brought him to the institution in the first place. Simply staying in the institution for a long period of time is anti-therapeutic.

The second point of the argument, based on testimony from a number of experts, was that in order to have a successful treatment program within a fairly short period of time one has to establish a therapeutic rapport, a voluntary treatment relationship. If that relationship cannot be established in the specified period of time, then the prognosis for successful treatment for

the mentally ill patient is poor. Although this position does not apply fully to mental retardation, there are still some analogies.

Since the prognosis for successful treatment diminishes as the patient stays longer and because of the severe anti-therapeutic consequences from institutionalization, we argued in court that it would be illegal to keep a person involuntarily confined, using treatment as the only justification for the civil involuntary commitment.

I think we are going to see a lot more focus on children. They are such a valuable resource. In Texas there is now a case focusing specifically on rehabilitation of juveniles between the ages of approximately 10 and 21. The Facilities and Institutions Branch of the Civil Rights Division, U.S. Department of Justice, has been ordered into the case by Judge Justice just as the U.S. Government was ordered into the Wyatt litigation by Judge Johnson. That is going to be perhaps the first case to explore in a systematic way the right to treatment for the mentally ill and mentally retarded juvenile (juvenile deliquents in this instance) and the standards for adequate treatment for those juveniles.

I would predict both by nudging the U.S. Department of Labor to enforce absolutely explicit provisions already on its books and by elaborating the constitutional argument (the 13th Amendment) we are going to see a radical change in institutional peonage practices. When I go into court on the institutional peonage issue, perhaps the first occasion will be with Bruce in the Dale case in New York, I will be taking the position that I believe in, which is that any labor for the maintenance of the hospital, including working in the laundry room or in the cafeteria, will violate the 13th Amendment rights of the patient if he does not agree to do that work voluntarily. Voluntary will not only mean the most obvious kinds of requirements like threatening not to release the patient if he does not perform the work but also will mean without a lot of very subtle threats which we are all aware of that could be brought to bear on the patient. It will mean informed voluntary consent in the same sense that that term is used with regard to searches under the 4th Amendment.

I think there will be a tremendous emphasis on the models and standards for community treatment facilities. I think implicit in Wyatt, but not articulated, is the phasing out and maybe phasing down of our large warehousing institutions. That requires the creation of a whole range of community facilities. However, to prevent the dumping of the patients, it requires the courts to get into the business of setting standards for nursing homes, respite centers, day care centers, community mental health centers and the other various alternatives. In the near future there is going to be a lot

of hard thinking and work in this area by lawyers and program people. The contracting for services outside of facilities and the involvement of the private sector are very healthy.

The real question is the method to provide these services outside of the institution. Some states may try a voucher system, i.e., give the parent a particular sum of money and let the parent spend it on a range of alternatives - some state-sponsored and some sponsored by the private sector. Free enterprise and competition may bring the standards up in this area. These service modules will also have to be policed, and I am sure that there will have to be minimum standards set either by program people or through court cases and court orders.

There will be a general rise of consumerism. There will be an increase in accountability. In a sense, it will make all of your jobs more difficult. It will be threatening, but the National Association for Retarded Children and the National Association of Mental Health, which have not been especially active in this area, will be hiring staff lawyers who will become the patients' advocates or representatives, attempting to play a role in all of the decision making processes, and reviewing the important decisions that have traditionally been purely discretionary for the superintendents, treating physicians and administrators. This will come. It will be troublesome and obviously it can be overdone and distracting and can create inefficiency. I just hope everyone will work together so that we have review, due process and accountability as we have in other areas of human services.

One thing that came up yesterday was that there is a real lack of communication and information. The national council, which Bruce described, would like to play a role in this area. In the meantime, we cannot make guarantees, but we would be happy to try to serve as a funnel for information, disseminating information about federal monies available for implementation, alternative models, less restrictive community facilities and other implementation plans that states develop and systems which they find effective. We will be keeping updated, accurate summaries of the cases that are being brought across the country, and we will try to receive and file accurately and give out this information upon request. I hope you will both send us information and make requests.

Mr. Horowitz: To continue with Paul's comments, not only do patients become institutionalized but also staff very frequently become institutionalized. I guess I first learned this in the prison setting. I suppose that one might think in the future in terms of setting minimum standards, or in terms of court orders or whatever, of some assurance that staff do not stay within an institution for more than an appropriate period

of time - five years, three years, whatever, depending on the level of staff involvement. Otherwise, I suspect we are going to have a counterproductive system where the staff just becomes too institutionalized. This might well become part of the court orders, the due process arguments, and, in my view, certainly should be considered as part of the standards that the profession develops.

Mr. Rosen: I have had the opportunity to work with these attorneys both at Partlow and at Willowbrook. It was not the most comfortable role. However, I definitely felt during that period that their objectives and my purpose in being there were for the good of the total program. I also felt that the legal profession had finally joined us. I did not view them as adversaries but as advocates for good programs.

Having the legal professions dramatically bring forth the problems that exist in institutions and also indicate the lack of interest by some state officials of conditions in Partlow and Willowbrook was very gratifying to me. I am going to go back to Michigan and try to convince the superintendents and the state administrator in our state that it is about time that we had lawyers available to us, not attorneys who we can call on for occasional problems in the state office, but rather people who could collaborate with us in the development of programs which would benefit the retarded.

Probably in every state there are laws that exist which discriminate against the retarded, whether it has to do with driving, marriage or voting.

The attorneys now, in talking to superintendents and state administrators in various meetings across the country, realize that nobody knows better than superintendents how bad many institutions are. Most superintendents do not want a crowded, substandard facility. They are anxious to make the changes.

Although some of us look with some concern and apprehension at the movement and at the possibility of some innocent people being hurt along the way, we do, however, look forward to this new movement as a means of upgrading our programs. We have spent millions and millions of dollars in institutional operations. Yet we spend very little in the development of appropriate administrative or management personnel for these facilities. Bruce said the other day that the National Association of Superintendents of Public Residential Facilities' first attempt at obtaining a grant for this purpose failed. We are working with a university affiliated facility on another effort for a management program for superintendents.

We also have a problem removing the residents from these crowded institutions and placing them in the community. We need legal help. We hope that after this initial thrust by the

lawyers that they turn around and assist us with the problems which we face in placing the retarded in the community. I alluded to the fact that we can purchase services - medical, laundry, culinary and professionals services - from the community.

We are anxious to make placements. However, we have one major concern - placement of people in the community without someone there being accountable. At the present time accountability by someone in the community exists in very few states. Once the persons are placed in the community, they are supposedly under the social service agency or a mental health board. These people, unfortunately, do not assume total responsibility. If an individual gets into trouble, is hurt, or is taken advantage of by someone, they do not go to the community agency. Rather, they are referred to the institutional superintendent. With these continued experiences, the superintendent becomes reluctant to make community placements.

We have to develop a system, whether it is an advocacy system, or whether it is with one of the community agencies, so that when that individual is released from the institution, he is legally transferred, just as he is legally admitted to the superintendent. Within the institution, if the child is hurt, mistreated, or does not receive the right treatment, the superintendent is responsible. This is not the case in the community. By the way, this is why the parents are so reluctant to have their children placed in the community. If their child fails in a program, there is usually nobody they can go to, or they have a frustrating experience going through a series of agencies and usually end up back with the superintendent. Until this situation is rectified, superintendents will not discharge the severe and the profoundly retarded. I would like to see some lawsuits against agencies in the community that are neglecting their responsibility for developing programs and for supervising persons that are mentally retarded in the community.

I welcome the involvement of the legal profession. I certainly hope that the state administrators also move their attorneys general out of the state capitols and down to the residential facilities. We need them on the local scene. We need those people assigned to the institutions just as we require a psychologist, an educator, or social worker to advise us what we should be doing. We need them to sit in the classification, admission and evaluation meetings so that we can develop a comprehensive program which will protect a retarded person's legal rights, medical rights and right to education, as well as many more basic areas. We have neglected this aspect of our program in our society for too long.

Mr. Horowitz: I see lawyers much like a hammer. We can either help you build a building or we can pound you on the thumb.

It largely depends on the way you will use us. If we are used cooperatively, we can help you build that building; but sometimes we may have to pound some thumbs. If there is more I can say, it would be to institutionalize a system of advocacy right within the system for the client. I think it can be done; Sam and I have been talking about doing it in Washington State, and we are close to actual implementation. I believe we can use federal money to do this. The Social Service titles provide that legal services are one of the eligible services.

Maybe you will need more lawyers. I have suggested that we should start with at least two attorneys to represent the residents with their problems whether it is the right to treatment, proper medical care, voting rights, the right to marriage, their own problems of consumer protection or anything similar. These lawyers can also assist you in improving your programs. Sometimes the lawyers will be adverse to you because their basic duty must be to their clients. Sometimes you and the client will not see eye to eye, or you and the lawyer might not see eye to eye.

In this way, when you nave built client advocacy right into the system, when you have institutionalized such a system, it seems to me you have built change into that system. Hopefully, you are building progressive change.

Robert Burt asked me should the advocates necessarily be lawyers. I do not think it should always be exclusively attorneys. However, initially I think that lawyers should be used because legal rights have been so neglected over such a long period of time. These legal rights have now moved over into other areas to assure the delivery of other rights. So I would suggest to you that if you are interested in institutionalizing, you might want to consider this possibility.

The community retardation laws in Washington State (some of you might have this also in the mental health laws) have a provision for offering social services or the coordination of social services. The attorney general issued an opinion that said this provision could mean the provision of legal services to the retarded in the community, not just in the institutional setting. Community services are provided through county boards in our state.

Legal services should be and are available to retarded people in the community through the same operation. I would again suggest that the best way to change the system is to institutionalize advocacy for those people who have never had it before. We have seen this in our legal services, in the development of the labor movement in this country and in many other precedents.

Mr. Ennis: Unfortunately, the lawyers at this conference have been represented basically as the only people really wanting progressive change and that is not true. Every single standard which we developed in the Wyatt case was generated not by us but by professional people who had an enormous input into the case, such as Dave Rosen. Other lawsuits are pending right now (10 of them) and literally hundreds more are going to be filed within the next few months and next few years. If we do not continue to get that kind of help from professionals, then the lawyers are going to have to do something that they are not equipped to do. The lawyers are going to have to start developing the standards and procedures. We really need lots of help. We had it in the past, and we are going to need more of it in the future. So far, the number of professionals who have been willing to help is very small. We need much more input from professionals. I am really seriously soliciting at this point any professional people who want to help in designing how the lawsuits now and in the future are going to develop.

Mr. Johnson: I guess the federal government is involved with almost all aspects of this movement - the Office of Education, the Health Services and Mental Health Administration, the Social and Rehabilitation Service, etc. I do not think, however, that we have a general position among all those different entities. We are as spread out as the states are. At least in our region, I think the philosophical viewpoint and goal is to assist the state in any way possible to develop the kinds of programs that will enable the mentally retarded or other handicapped persons to reach their goals or to fully realize their talents.

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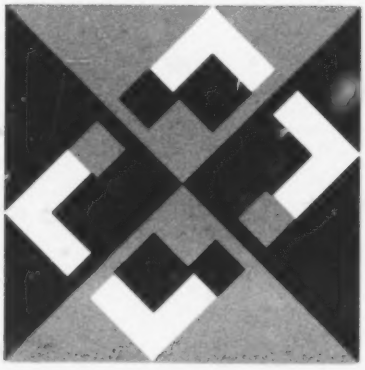

APPENDICES

APPENDIX A

ANNOTATED BIBLIOGRAPHY

A. IMPORTANT RECENT PUBLICATIONS ON THE CIVIL RIGHTS OF THE MENTALLY RETARDED

Three new important references, not listed in the bibliographies which follow in this issue, are now available to the interested mental health advocate:

Basic Rights of the Mentally Handicapped,[1] developed by the Mental Health Law Project, focuses on three rights: right to treatment; right to compensation for institution-maintaining labor; and right to education. The 123 page booklet demonstrates how and why litigation can be a useful tool for vindicating these rights.

"An Essay on the Legal Rights of the Mentally Retarded," by Dennis E. Haggerty, et al., appears in The Family Law Quarterly, Vol. 6, No. 1, Spring, 1972. It provides a brief discussion of the civil and criminal rights of the mentally retarded.

"Civil Rights of the Mentally Retarded: Some Critical Issues," by Charles W. Murdock appears in Notre Dame Lawyer, October, 1972, Vol. 48, p. 133. The article discusses guardianship, institutionalization and education as they affect the rights of the mentally retarded.

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[1] Basic Rights of the Mentally Handicapped may be purchased on a prepaid basis for $1.25. All orders should be sent to the National Association of Mental Health, 1800 Kent Street, Arlington, Virginia 22209.

B. RIGHT TO TREATMENT

Bazelon, David L., "Implementing the Right to Treatment," The University of Chicago Law Review, Vol. 36, p. 742, 1969.

Burris, Donald S., (Ed.), 'The Right to Treatment," A Symposium, reprinted from the Georgetown Law Journal, Vol. 57, March, 1969.

Chambers, David L., "Alternatives to Civil Commitment of the Mentally Ill: Practical Guides and Constitutional Imperatives," Michigan Law Review, Vol. 70, No. 6, May, 1972.

"Civil Restraint, Mental Illness and the Right to Treatment," Yale Law Journal, Vol. 77, p. 87.

Constitutional Rights of the Mentally Ill, Hearings before the Subcommittee on Constitutional Rights of the Committee on the Judiciary, United States Senate, 91st Congress, November, 1969 and August, 1970.

Ennis, Bruce, Prisoners of Psychiatry: Mental Patients, Psychiatrists, and the Law, Harcourt Brace Jovanovich, Inc., New York, 1972.

"Law and Psychiatry," A symposium, The American Criminal Law Review, Vol. 10, No. 3, 1972, published by the American Bar Association.

Rivera, Geraldo, Willowbrook: A Report on How It Is and Why It Doesn't Have To Be That Way, Vintage Books, New York, 1972 (paperback).

"The Administration of Psychiatric Justice: Theory and Practice in Arizona," Special Project, Arizona Law Review, Vol. 13, No. 1, 1971.

C. RIGHT TO AN EDUCATION

1. Abeson, Alan, "Movement and Momentum: Government and the Education of Handicapped Children," Law Review, Exceptional Children, September, 1972.[1]

Article gives a brief synopsis of recent activities which are reshaping educational opportunities for handicapped children, including new state and federal legislation, major attorneys' general rulings, major court decisions, and public awareness.

2. Abeson, Alan and Weintraub, Frederick J., "State Law for the Handicapped -- Essential Ingredients," Compact, August, 1971.[2]

Brief analysis of the relationship between different types of mandatory school laws and the development of programs for handicapped children.

3. "Ability Grouping in Public Schools: A Threat to Equal Protection?" Connecticut Law Review, 1:150, June, 1968.

Discussion of why the court in Hobson v. Hansen was incorrect in concluding that ability grouping on the basis of aptitude test scores is a denial of equal educational opportunity to the disadvantaged black.

4. Blatt, Burt, "Public Policy and the Education of Children with Special Needs," Exceptional Children, March, 1972.[1]

In the context of current legislation and models for special education, the article discusses the right to a public education in terms of labeling and stigma, current programs, standards and accountability, grass roots involvement, and the effective coordination of community resources.

5. Coleman, James, "The Concept of Equality of Educational Opportunity," Harvard Educational Review, 38(1), 1968, p. 7.

Traces evolutionary shifts in interpretation of the concept of "equality of educational opportunity," discussing what it has meant in the past, what it means now and what it is likely to mean in the future.

6. "Compulsory Education in the U.S.: Big Brother Goes to School," Comments, Seton Hall Law Review, 3:349, Spring, 1972.

Article discusses the educational system and the conflict between individual rights and administrative expediency. In particular, it focuses on compulsory education in terms of state power, decriminalization of the school laws, uniform appointment of guardians for the protection of children's rights, etc.

7. Dunn, Lloyd M., "Special Education for the Mildly Retarded -- Is Much of It Justifiable?" Exceptional Children, September, 1968.[1]

Examines the present form of special education programs and provides a blueprint for change. Article takes position that current special education programs are obsolete and violate students' civil rights as well as raising serious educational questions.

8. "Equality of Educational Opportunity: Are Compensatory Programs Constitutionally Required?" Southern California Law Review, 42:146, Fall, 1968.

Article focuses on the issue of whether local school districts can be judicially required to apply for and initiate compensatory programs under the mandate of the equal protection clause.

9. Ross, Sterling L., Jr.; DeYoung, Henry; and Cohen, Julius S., "Confrontation: Special Placement and the Law," Exceptional Children, September, 1971.[1]

Discussion of a number of major law suits brought against public schools with regard to labeling, testing procedures, and the effectiveness and harmfulness of special class programming for the educable mentally retarded.

10. Weintraub, Frederick J., "Recent Influences of Law Regrading the Identification and Educational Placement of Children," Focus on Exceptional Children, Vol. 4, #2, April, 1972.[3]

Reviews the historical, philosophical and major legal developments pertaining to the identification and placement of children in special classes and the implications of these developments.

11. Weintraub, Frederick J., and Abeson, Alan, "Appropriate Education for All Handicapped Children: A Growing Issue," Syracuse Law Review, to be published.

Article discusses some of the major legal developments regarding appropriate educational placement, and the implications of these developments for increasing the educational opportunities of handicapped children.

12. Weintraub, Frederick J.; Abeson, Alan; and Braddock, David, State Law and Education of Handicapped Children: Issues and Recommendations, Council for Exceptional Children, October, 1971.[4]

The book is designed as a guide to those seeking legal change in the area of educational opportunities for handicapped children. It includes a general discussion of the right to an education, identification and placement, administrative responsibilities, and a model statute for special legal provisions that handicapped children need.

13. Holliday, Albert E., "Implementing Education for Retarded Children," Pennsylvania Education, May-June, 1972, Vol. 3, #5, pp. 10-15.[5]

14. Han, Em, Special Miseducation--The Politics of Special Education," Inequality in Education, Nos. 3 and 4, Harvard Center for Law and Education, pp. 17-27.

15. "The Pennsylvania Court Orders," The Exceptional Parent, December/January, 1972, pp. 18-22.

Footnotes

[1] Single copies of reprints of articles from Exceptional Children are available from the Council for Exceptional Children Information Center, 1411 S. Jefferson Davis Highway, Suite 900, Arlington, Virginia 22202.

[2] Single copies of this article are available from the State Information Clearinghouse for Exceptional Children, CEC Information Center, 1411 S. Jefferson Davis Highway, Suite 900, Arlington, Virginia 22202.

[3] Single copies of this publication are available from Focus for Exceptional Children, 6635 E. Villanova Place, Denver, Colorado 80222, Price $.80.

[4] Copies may be purchased from the Council for Exceptional Children, 1411 S. Jefferson Davis Highway, Suite 900, Arlington, Virginia 22202, Price $3.25.

[5] Published by the Pennsylvania Department of Education, Education Building, Box 911, Harrisburg, Pennsylvania 17126.

GLOSSARY

amicus curiae - an individual or organization, neither plaintiff nor defendant, which, because of its expertise or interest, is allowed to become involved in the case as a "friend of the court." The involvement usually consists of submitting a brief containing supporting legal arguments to the court. Under extraordinary circumstances, the right to actually participate in the case and to present evidence and cross-examine witnesses can be granted, as was done in Wyatt v. Stickney, the landmark right-to-treatment case won in Alabama.

appeal - the process whereby a court of appeals reviews the record or written materials from a trial court proceeding to determine if errors were made which might lead to a reversal of the trial court's decision. If substantial errors are not found, the trial court's decision will be affirmed.

cause of action - a cause of action is the occurrence which has resulted in injury to one of a plaintiff's legally protected interests. A case is made up of one or more causes of action.

civil case or suit - a case brought by one or more individuals to seek redress of some legal injury (or aspect of an injury) for which there are civil (non-criminal) remedies. Most right-to-treatment and right-to-education cases are civil, such as Wyatt v. Stickney and Mills v. District of Columbia.

class action - a case brought on behalf of both the plaintiffs who are actually named in the suit and of all other persons similarly situated, to vindicate their legally protected interests. The Mills v. District of Columbia case was brought on behalf of 12-year-old Peter Mills and six other school-age children who were named in the complaint, as well as all other exceptional children now residing in the District or those who will be living there in the future.

complaint - a legal document submitted to the court by potential plaintiffs in which they inform the court and the defendants that they are bringing a lawsuit and set out the underlying causes of action.

consent agreement - an out-of-court agreement reached by the parties to a suit, which may be formally approved by the court. In Pennsylvania Association for Retarded Children v. Pennsylvania, a Pennsylvania court ordered that all mentally retarded children be given access to a free public program of education

appropriate to their learning capabilities, pursuant to a consent agreement worked out between plaintiffs and defendants.

constitutional right - a legal right which is based on the United States Constitution or on a state constitution. Equal protection and due process of law are constitutional rights.

court systems - there are two court structures in the United States: the federal courts (consisting mainly of federal district courts where cases are tried, the U.S. Courts of Appeal for the 11 circuits or areas of the country, and the U.S. Supreme Court) and the state courts (consisting of trial-level courts called by various names, and one or two levels of appeals courts, depending on the size of the state and its caseload). Decisions by the highest court in a state are reviewable by the U.S. Supreme Court.

criminal suit - a case brought by a public prosecutor against someone who is alleged to have committed a wrong for which there are statutory criminal penalties.

damages - money awarded by a court to someone who has been injured (the plaintiff) and which must be paid by the one who is responsible for the injury (the defendant). Normal damages are awarded when the injury is judged to be slight; compensatory damages are awarded to repay or compensate the injured person for the injury incurred, such as medical expenses, pain and suffering, and mental anguish; and punitive damages are awarded when the injury is judged to have been committed maliciously or in wanton disregard of the injured plaintiff's interests.

declaratory relief - a remedy granted by a court where the court declares or finds that plaintiffs have certain rights. A request for declaratory relief is usually coupled with a request for injunctive relief where the court orders defendants to take or refrain from taking certain actions.

defendant - the person against whom an action is brought because he is allegedly responsible for violation of one or more of a plaintiff's legally protected interests. The defendants in the Mills right-to-education case included the Board of Education of the District of Columbia and its members, the Superintendent of Schools for the District and subordinate school officials, the Mayor and certain subordinate officials, and the District of Columbia.

defense - a reason cited by a defendant why a complaint against him is without merit or why he is not responsible for the injury or violation of rights as alleged by the plaintiff. A defense might be that his actions were privileged, or that the plaintiff consented to the action, or even that procedural rules for bringing the suit against him were not properly followed.

discovery - the process by which one party to a civil suit can find out about matters which are relevant to his case, including information about what evidence the other side has, what witnesses will be called and so on. There are several discovery devices for obtaining information: depositions and interrogatories to obtain testimony, requests for documents or other tangibles, or requests for physical or mental examinations.

due process of law - a right to have any law applied reasonable and with sufficient safeguards, such as hearings and notice, to insure that an individual is dealt with fairly. Due process is guaranteed under the Fifth and Fourteenth Amendments to the U.S. Constitution. In Mills v. District of Columbia, the judge held that due process of law requires a hearing prior to exclusion, termination or classification of a student into a special program.

equal protection of law - a right not to be discriminated against for any unjustifiable reason, such as because of race or handicap. Equal protection is guaranteed under the Fourteenth Amendment.

expert witness - a person called to testify because he has a recognized competence in an area. For example, one expert in the Mills right-to-education case had a doctorate in the field of special education, was an author of numerous professional publications pertaining to exceptional children, and was a consultant to prestigious advisory committees involving education.

injunctive relief - a remedy granted by the court forbidding or requiring some action by the defendant. Injunctive relief includes temporary restraining orders, and preliminary and final injunctions. The difference among these types of relief is that they are issued for varying lengths of time, at various stages of the litigation process and on the basis of varying degrees of proof.

judgment - an order by a judge after a verdict has been reached which sets out what relief is to be granted to the winning side. For example, in the Mills case, the judge required the District of Columbia Board of Education to provide an appropriate publicly supported education to every exceptional child and set out elaborate hearing procedures, among other relief which was granted.

motions - a request to the court to take some action or to request the opposing side to take some action relating to a case. Motions generally relate to pre-trial or trial procedures, such as a motion for a more definitive statement, a motion to dismiss the case, etc.

next friend - a person who represents the interests of a minor or an incompetent in a legal action. A next friend or guardian ad litem is usually a parent or guardian but may be an important person in the community or an interested organization. In Mills, U.S. Congressman Ronald Dellums; the Reverend Fred Taylor, a clergyman; the Director of FLOC (For Love of Children), an organization seeking to alleviate the plight of homeless and dependent children in the District; and the District's Welfare Rights Organization represented some of the named plaintiffs as next friends.

plaintiff - a person who brings a suit in court in the belief that one or more of his legal rights have been violated or that he has suffered legal injury.

pleadings - a term which encompasses all of the preliminary steps of complaint-answer-replies used to narrow a case down to the basic issues of law and fact. It is also used more specifically to refer to a plaintiff setting forth his cause of action and the relief which he is requesting from the court.

precedent - a decision by a judge or court which serves as a rule or guide to support other judges in deciding future cases involving similar or analogous legal questions. In Mills, the judge cited some famous education decisions as precedents, including Brown v. Board of Education, outlawing segregated schools, and Hobson v. Hansen, outlawing the track system in the District of Columbia. Mills can now be cited as precedent by other courts for finding a constitutional right to education.

private action - a case brought on behalf of one or more individuals to vindicate violation of their legally protected interests. As distinguished from a class action, where the relief will apply to all persons similarly situated or within the class represented by the plaintiffs, any relief granted in a private action applies only to those plaintiffs actually before the court.

procedural right - a right relating to the process of enforcing substantive rights or to obtaining relief, such as the right to a hearing, the right to present evidence in one's defense, or the right to counsel.

relief - a remedy for some legal wrong. Relief is requested by a plaintiff, to be granted by a court, against a defendant. For example, in Wyatt v. Stickney, as part of the relief, the court set standards for minimum constitutionally and medically adequate treatment at state hospitals in Alabama.

settlement - an out-of-court agreement among parties to a suit, which resolves some or all of the issues involved in a case.

statutory right - a right based on a statute or law passed by a unit of federal, state or local government. The Fair Labor Standards Act is a federal statute establishing a right to a minimum wage for certain categories of workers, including by amendment, patients institutionalized in state hospitals and schools for the mentally retarded.

substantive right - an essential right such as the right to free speech and religion or to be free from involuntary servitude, usually found in the Bill of Rights.

test case - a case brought to establish a legal principle, as well as to vindicate rights of the parties involved in the specific case. Once principles are established in one court, they can be cited as precedent for decisions by other judges or other courts. Wyatt v. Stickney is now a precedent for other judges to find a constitutional right to treatment.

tort - a civil wrong for which a private individual may recover money damages. Torts include, for example, assault and battery, intentional infliction of mental distress, false imprisonment and invasion of privacy.

verdict - a decision by a judge or jury in favor of one side or the other in a case.

POSITION ON THE PEONAGE ISSUE

This workshop, recognizing the seriousness of the problem of institutional peonage, and inconsideration of patients' therapeutic interests and also their 13th Amendment rights, voted to endorse the substance of the following position, although not its specific language.

A. Training Tasks and Labor

1. Residents may be required to perform vocational training tasks which are part of an organized vocational-educational training program and which do not involve the operation and maintenance of the institution, subject to a rebuttable presumption that an assignment of longer than three months to any task is not a training task, provided the specific task or any change in task assignment is:

   (a) An integrated part of the resident's habilitation plan and approved as an habilitation activity by a Qualified Mental Health Professional responsible for supervising the resident's habilitation;

   (b) Supervised by a staff member to oversee the habilitation aspects of the activity, and reviewed regularly and at least monthly and adjusted if this is therapeutically indicated.

   (c) And further provided that the work skills being taught in such programs are relevant to opportunities which exist in the outside community.

   (d) The group further felt that when such labor is undertaken for more than four hours a day or 20 hours a week, and thus approaches a normal part-time or full-time work week, the resident is probably ready for placement to a suitable, compensated work assignment outside the institution.

2. Residents may voluntarily engage in habilitative labor at nonprogram hours for which the institution would otherwise have to pay an employee, provided the specific labor or any change in labor is:

   (a) An integrated part of the resident's habilitation plan and approved as a habilitation activity by a Qualified Mental Retardation Professional responsible for supervising the resident's habilitation;

(b) Supervised by a staff member to oversee the habilitation aspects of the activity; and reviewed regularly and at least monthly and adjusted if this is therapeutically indicated.

(c) Compensated in accordance with the minimum wage laws of the Fair Labor Standards Act, 29 U.S.C. 206 amended, 1966, or the prevailing wage for such work in the community, whichever is greater.

B. Personal Housekeeping

Residents may be required to perform tasks of a personal housekeeping nature such as the making of one's own bed.

C. No more than 1/4 of the payments to residents pursuant to this paragraph shall be applied to the costs of institutionalization.

D. Staffing shall be sufficient so that the institution is not dependent upon the use of residents or volunteers for the care, maintenance or habilitation of other residents or for income-producing services. The institution shall formulate a written policy to protect the residents from exploitation when they are engaged in productive work.

E. Institution Maintenance

Some members of the group felt that the 13th Amendment puts an absolute ban on the institution from requiring a resident to perform labor which involves the operation and maintenance of the institution (such as working in the cafeteria or laundry room or performing janitorial functions) or for which the institution is under contract with an outside organization. This position paper does not express a group opinion on the constitutionality or unconstitutionality of such labor. The group did agree that if a resident may regularly be required to perform such labor, it must be therapy or training for the resident and must be carefully safeguarded as therapeutic or training labor according to the provisions of A. 1. (a) - (d) above.

The group further agreed that as a general principle, payment for labor is an important part of the therapeutic value of the labor for the patient.

"THE RIGHTS OF THE MENTALLY HANDICAPPED"

Sir Francis Drake Hotel
San Francisco, California

June 14 - 16, 1972

AGENDA

Tuesday — June 13

4:00 - 8:00 p.m. REGISTRATION—Mezzanine

Wednesday — June 14

8:00 - 9:00 a.m. REGISTRATION—Mezzanine

9:00 - 9:30 a.m. WELCOME – OPENING REMARKS
Dr. Samuel Ornstein
Mr. Donald Horowitz

9:30 - 10:00 a.m. KEYNOTE ADDRESS
The Honorable David Bazelon, Chief Judge
U.S. Court of Appeals
District of Columbia Circuit

10:00 - 10:30 a.m. STATUS OF THE STATES – AN OVERVIEW
Mr. Robert Gettings

10:30 - 10:45 a.m. COFFEE

10:45 - 11:45 a.m. STATE PROGRAMS – PROBLEMS OF THE DEFENDANTS
Mr. David Ray

11:45 - 1:00 p.m. LUNCH

1:00 - 1:30 p.m. NATIONAL COUNCIL ON THE RIGHTS OF THE MENTALLY IMPAIRED
Mr. Bruce Ennis

1:30 - 2:30 p.m. CASE STUDY – Wyatt vs. Stickney
Panel Moderator: Dr. Samuel Ornstein
Dr. John Hottell
Mr. Jerry Wood
Mr. George Dean

2:30 - 2:45 p.m. COFFEE

2:45 - 3:45 p.m. CASE STUDY – Pennsylvania Association for Retarded Children vs. Commonwealth of Pennsylvania
Panel Moderator: Mr. Donald Horowitz
Mr. Thomas Gilhool

3:45 - 4:15 p.m. NATIONAL ASSOCIATION FOR RETARDED CHILDREN
Dr. Philip Roos

4:15 p.m. ADJOURN

Thursday — June 15

WORKSHOP EXPERIENCE

Method – Conference participants will form two groups. A conference consultant will serve as group leader and recorder.

Assignment – Be prepared to discuss and describe current state programs, policies, and laws, relating directly to the issues brought out of recent law suits.

9:00 - 10:15 a.m.	LEAST RESTRICTIVE HABILITATION SETTING (Group A)
	ADMITTANCE STANDARDS AND EVALUATION (Group B)
10:15 - 10:45 a.m.	COFFEE – FREE DISCUSSION
10:45 - 12:00 Noon	RESIDENT LABOR (Group A)
	RIGHT TO EDUCATION (Group B)
12:00 - 1:15 p.m.	LUNCH
1:15 - 2:30 p.m.	VOLUNTARY AND INVOLUNTARY COMMITMENT (Group A)
	PAYMENT FOR CARE – EQUITY OF PAYMENT AND RIGHT TO SERVICES (Group B)
2:30 - 3:00 p.m.	COFFEE – FREE DISCUSSION
3:00 - 4:15 p.m.	RIGHT TO HUMANE PHYSICAL AND PSYCHOLOGICAL ENVIRONMENT (Group A)
	POST INSTITUTIONALIZATION PLAN AND PLACEMENT (Group B)
4:15 p.m.	ADJOURN

Friday — June 16

9:00 - 10:30 a.m.	REPORTS BY GROUP RECORDERS AND DISCUSSION
10:30 - 10:45 a.m.	COFFEE
10:45 - 12:00 Noon	PANEL DISCUSSION THE PROBLEM OF IMPLEMENTATION: THE FUTURE OF THE MENTALLY HANDICAPPED Moderator: Mr. Donald Horowitz Mr. Isaac Johnson Mr. David Rosen Mr. Bruce Ennis Dr. Stonewall Stickney Mr. Paul Freidman

ROSTER OF PARTICIPANTS

Honorable David Bazelon
Chief Judge
U.S. Court of Appeals
District of Columbia Circuit
United States Courthouse
Washington, D.C. 20001

Mr. Philip Benson
Office of Developmental Disabilities
Dept. of Social and Health Services
Olympia, Washington 98504

Mr. Larry Bettis
Deputy Attorney General for Dept. of Health, Welfare and Rehabilitation
Union Federal Building
Room 205
308 No. Curry Street
Carson City, Nevada 89701

Dr. Robert Burt
University of Michigan Law School
Ann Arbor, Michigan 48104

Mrs. Shirley N. Cantor
Assistant Attorney General
State Capitol Building
Phoenix, Arizona 85007

Mr. George W. Dean, Jr.
Attorney at Law
P. O. Box 248
Destin, Florida 32541

Dr. Charles Dickson
Clinical Administrator
Mental Hygiene and Mental Retardation
480 Garletti Way
Reno, Nevada 89505

Dr. Giulio diFuria
Superintendent
Western State Hospital
Ft. Steilacoom, Washington

Mr. James Doak
State Coordinator for Mental Retardation
Room 217 - McKay Building
338 Denali Street
Anchorage, Alaska 99501

Mr. David Duehlmeier
Area Administrator
Division of Mental Health
State Office Building
Boise, Idaho 83707

Mr. Bruce Ennis
Attorney at Law
84th Fifth Avenue
New York, New York 10011

Mr. Landon Estep
Attorney at Law
2525 Seattle First National Bank Building
Seattle, Washington

Dr. Walter Fox
Assistant Commissioner for Mental Health Services
1624 W. Adams Street
Phoenix, Arizona 85007

Mr. Paul Friedman
Center for Law and Social Policy
1600 - 20th St., N.W.
Washington, D.C. 20009

Dr. Charles Gardipee, Chief
Bureau of M.R. and Disabilities Services
State Dept. of Public Health
2151 Berkeley Way
Berkeley, California 94704

Mr. Robert M. Gettings
Executive Director
National Association of
Coordinators of State
Programs for the Mentally
Retarded, Inc.
2001 Jefferson Davis Hwy
Suite 802
Arlington, Virginia 22202

Mr. Thomas Gilhool
Attorney at Law
No. 1, North 13th Street
Philadelphia, Pennsylvania 19102

Dr. Russell L. Guiss
Superintendent
Dammasch State Hospital
Wilsonville, Oregon 97070

Mr. Stan Herr
National Legal Aid and
Defender Association
1601 Connecticut Ave., N.W.
Washington, D.C. 20009

Mrs. Martha Hislop
Assistant Regional Mental
Retardation Consultant
Regional Rehab. Services
Administration, SRS
Dept. of HEW
50 Fulton Street
Federal Office Building
San Francisco, California 94102

Mr. Benton Hom
Deputy Coordinator
Plans and Budgets
State Office of Mental
Retardation
915 Capitol Mall
Sacramento, California 95814

Mr. John E. Horner
Executive Assistant
Mental Retardation Services
2570 Center Street, N.E.
Salem, Oregon 97310

Mr. Donald Horowitz
Senior Assistant Attorney
General
Chief, Social and Health
Services Division
P. O. Box 1788
Olympia, Washington 98504

Dr. John V. Hottel
Deputy Commissioner
Mental Health
Interim Superintendent
Partlow State School & Hospital
Tuscaloosa, Alabama 35401

Mr. Isaac Johnson
State Representative for
Rehabilitation Services
Dept. of HEW
Regional Office X
Arcade Building, Room 5019
1321 - 2nd Avenue
Seattle, Washington

Mr. Frank Junkin
Superintendent
Fircrest School
15230 - 15th St., N.E.
Seattle, Washington

Mrs. Pat Moore
Office of Developmental
Disabilities
Dept. of Social and Health
Services
P. O. Box 1788
Olympia, Washington 98504

Mr. Leonard Long
Supervisor, Community Services
Office of Developmental
Disabilities
Dept. of Social and Health
Services
P. O. Box 1788
Olympia, Washington 98504

Mr. Tom Manual, Jr.
Deputy Regional Attorney
Office of General Counsel
50 Fulton Street, Room 4009
San Francisco, California 94102

Mr. Charles Martin
Coordinator for Mental Retardation
1802 W. Jefferson Street
Phoenix, Arizona 85007

Mrs. Genevieve Merrill
Director
Developmental Disabilities Planning
Dept. of Social and Rehabilitation Services
Box 1189
Boise, Idaho 83702

Mr. Jack Middleton
Associate Administrator
Division of Mental Hygiene and Mental Retardation
P. O. Box 2460
Reno, Nevada 89505

Mr. Paul Murphy
Assistant Attorney General
Dept. of Social and Health Services
P. O. Box 1788
Olympia, Washington 98504

Dr. Samuel L. Ornstein
Chief
Office of Developmental Disabilities
Dept. of Social and Health Services
P. O. Box 1788
Olympia, Washington 98504

Mrs. Elizabeth Palmer
Acting Assistant Attorney General
6000 Street Building
350 McAllister
San Francisco, California 94102

Mr. Ray Preston
Assistant Attorney General
Department of Law
Pouch K
State Capitol
Juneau, Alaska 99801

Mr. David B. Ray, Jr.
Assistant Commissioner
Director of Mental Retardation Services
Division of Mental Retardation
300 Cordell Hull Building
Nashville, Tennessee 37219

Dr. Aldon Roat, Chief
Mental Health Division
Hawaii State Department of Health
P. O. Box 3378
Honolulu, Hawaii 96801

Dr. John P. Rollins, Chief
Professional Services
Alaska Psychiatric Institute
2900 Providence Avenue
Anchorage, Alaska 99504

Dr. Philip Roos
Executive Director
National Association for Retarded Children
2709 Avenue "E" East
Arlington, Texas 76001

Mr. David Rosen, Chairman
National Association of Superintendents of Public Residential Facilities
The Howard Plaza
29350 Southfield Road
Suite 120
Southfield, Michigan 48076

Mr. Terry Ross
California Association for Retarded Children
Forum Building
Sacramento, California 95813

Dr. Stonewall B. Stickney
Commissioner for Mental Health
Dept. of Mental Health
502 Washington Avenue
Montgomery, Alabama 36104

Mr. Kent Taylor
Assistant Attorney General
State House
Boise, Idaho 83707

Mr. Dick Wetmore
Assistant Regional Attorney
Dept. of Health, Education,
and Welfare
1321 - 2nd Avenue
MS 624
Seattle, Washington 98101

Mr. Jerry Wood
Deputy Attorney General
State of Alabama
502 Washington Avenue
Montgomery, Alabama 35104

Dr. Garret H. Yanagi
Coordinator for Mental
Retardation
Waimano Training School
and Hospital
Pearl City, Oahu
Hawaii 96782

Mr. Frank Yap
Deputy Attorney General
Hawaii State Capitol
Honolulu, Hawaii

Dr. John J. Blalock, Head
Mental Health Team for
Courts and Corrections
Hawaii State Department of
Health
P. O. Box 3378
Honolulu, Hawaii

Mr. Terry O'Malley
Assistant Attorney General
Commonwealth of Massachusetts
State House
Room 373
Boston, Massachusetts

Mr. Wm. Allen Ziegler, Jr.
Program Assistant
National Association of
Coordinators of State
Programs for the Mentally
Retarded, Inc.
2001 Jefferson Davis Highway
Suite 802
Arlington, Virginia 22202

APPENDIX F

SOURCES OF INFORMATION ON LITIGATION

National Center for Law and the
Handicapped, Inc.
1235 No. Eddy Street
South Bend, Indiana 46617
(219) 288-4751

State-Federal Information Clearinghouse
for Exceptional Children
Council for Exceptional Children
1411 Jefferson Davis Highway
Suite 900
Arlington, Virginia 22202
(703) 521-8820

Office of Mental Retardation
Coordination
Room 3744
HEW North Building
330 Independence, S.W.
Washington, D.C. 20201
(202) 962-5527

Center for Law and Social Policy
1600 20th Street, N.W.
Washington, D.C. 20009
(202) 876-0670

National Council on the Rights of
the Mentally Impaired
1600 20th Street, N.W.
Washington, D.C. 20009
(202) 876-0670